

**PROCEEDINGS**  
**First Annual Conference**  
of the  
**Model Reporting Area**  
for  
**Blindness Statistics**  
1962

U.S. DEPARTMENT OF  
HEALTH, EDUCATION, AND WELFARE  
Public Health Service

# PROCEEDINGS

## First Annual Conference of the Model Reporting Area for Blindness Statistics 1962

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE  
Public Health Service  
NATIONAL INSTITUTE OF NEUROLOGICAL DISEASES AND BLINDNESS  
NATIONAL INSTITUTES OF HEALTH  
Bethesda 14, Maryland

## FOREWORD

It is a curious paradox that while the blind have always been with us we know so little about them. The year 1962 may well prove to have been a turning point in the long and frustrating struggle to determine the magnitude of the problem of blindness, its causes, and the characteristics of the afflicted. Censuses, surveys, and projections of reported blind from a limited geographic area to the nation as a whole, have all been used from time to time. The problems of definition and lack of reliable medical information from respondents made it hazardous to use census or survey data for estimates. The sampling error inherent in projecting the data from one State to the entire country would make this approach infeasible.

In 1962 a group of States determined to do something about the vexing problems created by lack of adequate statistics on blindness. They joined together as the Model Reporting Area for Blindness Statistics and agreed, for statistical reporting reasons, to use a common definition of blindness, to collect certain essential information on each new case added to the register, to use the Standard Classification of the Causes of Blindness, and to keep their registers up-to-date. What this high resolve means for the cause of good statistics on the blind one can only guess. However, there is no gainsaying the fact that by speaking the same language, by agreeing to produce comparable and poolable data, the Model Reporting Area States are meeting a problem with action calculated to give the nation for the first time urgently needed information on an age-old disability. This information will guide decision making and bolster confidence in action taking.

The Proceedings of the 1962 Conference will reveal that agreeing to agree also carries certain responsibilities of which the States are well aware. It is hoped that sharing those responsibilities will, in the years to come, be a source of gratification to more than the 11 States that comprise the nucleus of the Area.

Richard L. Masland, M.D.  
Director, National Institute of  
Neurological Diseases and Blindness

# CONTENTS

	Page
I. Introduction . . . . .	1
II. Special Presentations . . . . .	2
III. Review of Standards for Membership in the Model Reporting Area for Blindness Statistics . . . . .	11
IV. Register Problems in the Model Reporting Area States and How They Will Be Met . . . . .	20
V. a. Status Report on The National Society for Prevention of Blindness Classification of the Causes of Blindness . . . . .	25
b. Development of Statistics on Causes of Blindness . . . . .	27
VI. Technical Details Pertaining to the Preparation of Annual Tabulations . . . . .	30
VII. Technical Details Pertaining to the Maintenance of Registers . . . . .	39
VIII. Other Business . . . . .	46

## APPENDIX

A. History of Blindness Statistics in the United States — <i>Ralph G. Hurlin, Ph.D.</i> . . . .	47
B. Declaration of Purpose of Model Reporting Area for Blindness Statistics — <i>Hyman Goldstein, Ph.D.</i> . . . .	50
C. The Register and Blindness Statistics in Canada — <i>Arthur N. Magill</i> . . . . .	54
D. Blindness Statistics and the National Society for the Prevention of Blindness — <i>John W. Ferree, M.D.</i> . . . .	57
E. The Importance of Uniform Reporting by Agencies for the Blind as Seen by the American Foundation for the Blind — <i>M. Robert Barnett</i> . . . . .	60
F. The North Carolina Project — <i>Dana Quade, Ph.D.</i> . . . .	64
G. Study of Association Between Factors of Pregnancy, Labor, and Delivery and the Occurrence of Blindness in Children in New York State — <i>Irving D. Goldberg</i> . .	68
H. Study of Survivorship and Causes of Death Among the Blind in Massachusetts — <i>Eugene Roget</i> . . . . .	77
I. The Need for Good Statistics on the Blind — <i>Irving D. Goldberg</i> . . . . .	80
J. List of Participants . . . . .	84

PROCEEDINGS OF THE FIRST ANNUAL CONFERENCE OF  
THE MODEL REPORTING AREA FOR BLINDNESS STATISTICS  
BETHESDA, MARYLAND  
MARCH 26-27, 1962

## I. INTRODUCTION

On March 26-27, 1962, the First Annual Conference of the Model Reporting Area for Blindness Statistics (MRA), sponsored by the National Institute of Neurological Diseases and Blindness (NINDB), was held in Bethesda, Maryland. In attendance were administrators and blindness register technicians, representing 9 of the 11 member States of the Model Reporting Area. These 9 States were respectively: Connecticut, Delaware, Kansas, Louisiana, Massachusetts, New Jersey, North Carolina, Rhode Island, and Vermont. No representatives were present from Hawaii due to the pressure of legislative activities there. New Hampshire was unable to send representatives because of illness and pressure of work. In addition there were present at the Conference representatives from the American Foundation for the Blind, National Society for the Prevention of Blindness, and the Canadian National Institute for the Blind. Federal agencies with blindness programs, represented at the Conference, included the Library of Congress, Office of Education, Office of Vocational Rehabilitation, Bureau of Family Services of the Social Security Administration, Bureau of State Services and National Institute of Neurological Diseases and Blindness of the Public Health Service. Also in attendance were representatives of the Service's National Institute of Mental Health.

The specific purpose of the meeting was to determine how statistics relating to the registered blind could be made more adequate and

meaningful. This meeting was the first of its kind to be held in this country. Chairman of the sessions was Dr. Hyman Goldstein, Chief of the Biometrics Branch, National Institute of Neurological Diseases and Blindness.

Dr. Richard L. Masland, Director of the Institute, in welcoming the participants, stressed the great interest in better statistics on the blind that was represented by the presence of the participants. He stated that the problem of accurate statistics on blindness was a source of very serious concern to the National Institute of Neurological Diseases and Blindness. As Director of the Institute, he served as a point of contact between the scientific community in its broadest sense, that is those concerned with research, and those concerned with services to the blind. Furthermore, he served as additional point of contact with the public. As a result, one of the most common questions submitted to him for reply dealt with the magnitude of the problem of blindness. In effect, this question had three aspects. How many blind people are there? What types of blindness do they represent? What are the major causes of blindness?

In the absence of accurate statistics, it was very difficult for Dr. Masland to give a meaningful response to this type of question which, obviously, had very important bearing in regard to the mobilization of adequate services for the prevention and management of blindness. It seemed to him that the opportunity, which was now developing under the aegis of the Model Reporting Area, as a unified effort in this direction, was a most important one of which full

advantage should be taken. In such an effort there is the important problem to be solved pertaining to the difficulty of obtaining uniform and meaningful criteria for the definition of blindness, for the classification of types of blindness, and for the inclusion or exclusion of cases from any register. Data will become more meaningful to the extent that they are derived under criteria established to insure uniformity in such definition, classification, and registration.

Dr. Masland pointed out that there are those who seriously question the various techniques utilized for obtaining data on incidence and prevalence, as derived from compilations of data from different States and different examiners. Such questions reflect a belief that really accurate data of this type are obtained by actual ophthalmological examination by a small group of competent examiners in order to keep the variation and error in diagnosis to a minimum. It was Dr. Masland's belief, however, that one must recognize that the type of data obtained must be influenced very significantly by the purpose for which such data are to be used. For example, if one was concerned particularly with the need to provide services, then one must be concerned with the incidence and prevalence of individuals with a condition clearly in need of such services. Quite often, this type of information might differ significantly from that required in order to determine, for example, the cause of disease.

In conclusion, Dr. Masland stressed the fact that the absolute essential for any nationwide effort of this type is the establishment of uniformity of objectives, uniformity of criteria, and uniformity of procedures. In his opinion, the Model Reporting Area for Blindness Statistics offered an important opportunity to move in this direction.

## II. SPECIAL PRESENTATIONS

- a. Dr. Ralph G. Hurlin, Chairman of the Committee on Operational Research, National Society for the Prevention of Blindness, presented a paper on "History

of Blindness Statistics in the United States." (See Appendix A for this paper as well as discussion that followed.)

This paper may be summarized as follows:

### SUMMARY:

The history of blindness statistics in this country goes back 130 years. It is notable not for the success of the efforts made, but rather for the deficiencies of the procedures used and, therefore, of the results obtained. Most of the statistics produced over the long period on prevalence, incidence, and causes of blindness have been misleading. Efforts in the past have centered on attempts to obtain much needed data of these three types — prevalence data to reveal the magnitude of the problem; incidence data, of much greater importance, to show the rate at which the impairment occurs; and cause data to guide research and efforts to prevent occurrence of the types of blindness that are preventable. A fourth category, statistics of the degree of visual impairment, has received scant attention although this information is of large significance for its own sake, and is essential if valid comparisons are to be made between the results of different surveys, censuses, or other studies.

The Bureau of the Census began enumerating blind persons in 1830 and continued these efforts through the census of 1930. In the first two of the eleven censuses, no instructions were given to the enumerators on this point, except that they should record at the bottom of each of their schedules the names of the persons enumerated thereon who were blind. In 1850, a column was inserted on the schedules in which to indicate which of the persons enumerated were blind. Until 1870 the enumerators were responsible for deciding who should be considered blind. At that census enumerators were instructed that only the "totally blind" were to be included, but total blindness was not defined nor was any test of the condition suggested.

In 1880 the first detailed instructions were given to enumerators. In this census the blind were to include both the totally blind

and the semiblind, but no person was to be enumerated as blind who could see well enough to read without great effort. At this census, enumerators were required to record special information concerning the blind persons enumerated and were paid an additional 5 cents per blind person returned. At this census, also, the enumerators' returns were supplemented by collection of names of blind persons from institutions and local physicians. There were, thus, several reasons for the increase in the ratio of enumerated blind persons to total population in this year, which was higher than in any previous or any later census.

Definitions and instructions changed in following censuses. In 1900, when the extra 5 cents per name was still paid for enumerating blind persons, individual schedules were mailed to the enumerated persons to obtain desired information concerning them and to test the accuracy of the enumeration.

The most detailed and extensive compilation of statistics concerning the enumerated blind persons was made in the special report compiled after the 1920 census. But these data, like those of the earlier censuses, are subject to doubt for many reasons. In the census of 1930, enumerators were required to enumerate as blind all persons "who cannot see well enough to read, even with the aid of glasses," but special information was not compiled concerning those enumerated as blind. The 1930 report on the enumerated blind concluded that no high degree of accuracy could be expected in a census of the blind carried out by the methods which had been found necessary in the attempts which had been made, and enumeration of blind persons has not been attempted in later censuses.

Mention should be made of some of the useful later developments, including the work of the Committee on Statistics of the Blind to encourage standardization of definitions and procedures; the work of Miss Evelyn McKay and Miss C. Edith Kerby in initiating consolidated annual statistics of pupils in schools of the blind, including statistics on causes of blindness; and the study of causes of blindness of

Aid to the Blind recipients of the Social Security Board's Bureau of Public Assistance in the early 1940's.

Probably the best statistics of blindness that have been produced so far in this country are those obtained in the monumental National Health Survey during the winter of 1935-36, from over 700,000 families located chiefly in 83 urban areas. In this survey interviewers received special training for interviewing and for recording the responses obtained. The data were carefully evaluated, and cause data on blindness and all other diseases and disabilities enumerated were supplemented insofar as possible by reference to clinic, hospital and physicians' records. But although the aim in this study was to find and enumerate all persons who were totally blind, no definition was provided in the instructions of the distinction to be made between the totally and the partially blind. The data on causes are much less detailed, and therefore much less useful, than would be cause data derived only from reports of qualified physicians.

Concluding, Dr. Hurlin referred to the efforts made by several State agencies in the late 1920's and 1930's to start or improve registers of known blind persons as statistical sources. He expressed belief that the present effort to develop reliable registers of blind persons could result in better statistics of blindness for this country than could be obtained through any general population census - a view that had been expressed 30 years ago when the Bureau of the Census was debating the desirability of attempting to count the blind in the population census of 1930.

- b. Dr. Hyman Goldstein, Chief, Biometrics Branch, National Institute of Neurological Diseases and Blindness, presented a paper on "Declaration of Purpose of the Model Reporting Area for Blindness Statistics." (See Appendix B for this paper as well as discussion that followed.) This paper may be summarized as follows:

## SUMMARY:

The Model Reporting Area for Blindness Statistics marks the first time that a group of States, the national voluntary blindness agencies, and the Federal Government have united to improve blindness statistics. Numerous attempts to secure statistical information on the blind on a national basis had been unsuccessful.

The Biometrics Branch, National Institute of Neurological Diseases and Blindness, explored the possibility of utilizing an existing instrument, the blindness register, to satisfy the continued need for uniform and reliable statistics on the incidence, prevalence, and causes of blindness. A uniform definition of blindness was essential to uniform statistics. Although the existence of reporting laws and mandatory registers in many States did not, in itself, insure uniform and reliable statistics, they did suggest a means by which such statistics could be achieved. The Biometrics Branch conceived the idea that States maintaining blindness registers would be willing to agree to collect specified essential data on each blind person and make concerted efforts to keep their registers up-to-date. A Planning Group for the Area was established, consisting of representatives of the National Society for the Prevention of Blindness, American Foundation for the Blind, Division of Chronic Diseases of the Public Health Service, and the Biometrics Branch, National Institute of Neurological Diseases and Blindness. The idea of a Model Reporting Area and its objectives were approved unanimously.

In order to determine the state of blindness registers throughout the country, staff of the Biometrics Branch visited 39 States thought to have such registers and, of these, 25 were found, in fact, to have them. Interest in the idea of a Model Reporting Area was extremely high in the State agencies. Only 5 States failed to show enthusiasm for the concept of such an Area. Much information was gathered in each State concerning the type of data collected, uses to which the registers were put, procedures in updating them, etc. The Planning Group

approved a set of standards for membership. An evaluation of each State's capacity and willingness to satisfy these standards was made by the Biometrics Branch. These evaluations, submitted to the Planning Group, constituted the basis for acceptance of 11 States into the Area.

Each Model Reporting Area State has subscribed to the Area objectives of improving blindness statistics and of stimulating research in the field of blindness (1) by encouraging complete reporting of the blind so that the register may more nearly reflect the true prevalence (number of blind persons in the State at a given time), and so that additions to the register may more nearly reflect the true incidence (number of persons in the State becoming blind during a given period); (2) by seeking to improve the records on the reported blind, so that the causes of blindness and the characteristics of the blind may more easily be studied; and (3) by using a common definition of blindness and standardized recording of essential items so that data from different States can more meaningfully be compared or pooled in an effort to arrive at national statistics on blindness.

The Biometrics Branch undertook to act in a coordinating and technical capacity for the Area, and agreed to furnish consultation and other assistance, where necessary, to the States accepted into the Area. The Branch's consultative services are also available, upon request, to States that either wish to (1) establish a State-wide blindness register to be maintained by a single State agency; (2) improve an existing register to meet the standards of the Model Reporting Area; or (3) where the register is large, to convert to a punch card system so that more effective utilization of register data for Area or local needs may be permitted. Working jointly with the Biometrics Branch in providing Public Health Service assistance to the States is the Neurological and Sensory Disease Service Branch of the Division of Chronic Diseases.

Statistics secured through the Model Reporting Area will be available to States, national, voluntary and other interested agencies, thus reducing, to some degree, requests from various



agencies to individual States for identical statistical data.

It is hoped that the existence of the Model Reporting Area will enlist the cooperation and support of the professional community of ophthalmologists and optometrists in bringing about better and more complete reporting of information on the blind. Only by such support can the Area best achieve its objectives.

- c. Mr. A. N. Magill gave a talk on "The Register and Blindness in Canada." (See Appendix C for this paper as well as discussion that followed.) This paper may be summarized as follows:

#### SUMMARY:

The nationwide blindness register in Canada dates back to the early days of the Canadian National Institute for the Blind (CNIB). This Institute had its beginning in 1900, at which time there was started in the Toronto area the Canadian Free Library for the Blind with the sole purpose of distributing library books to the adult blind. In 1916, under the guidance of Col. E. A. Baker, an over-all service program was instituted, resulting in a Federal Charter for the Institute in 1918 (1) on the basis of being a private organization and, thus, eligible to receive certain grants from various levels of Government and support from the general public, and (2) on the basis of responsibility for carrying out a nationwide rehabilitation program for the blind.

The Institute attempted soon thereafter to develop a register in order to determine the extent of the problem. Initially the names of the blind were secured from Canadian schools for the blind and through the insertion of advertisements in newspapers. Furthermore, after the CNIB had been successful in persuading the Canadian Government to allow persons, certified as blind by the Institute, to have radios license-free, many blind people made themselves known to it. The register was

established in 1918 with a Government and CNIB definition based on central visual acuity in the better eye of 3/60 with best correction. In each case an ophthalmological report was requested. This definition was changed in the 1930's to 6/60, both for the Government and CNIB. When a pension for blind people was made available in 1937, the CNIB, working with the Government, had to certify as to blindness of applicants. A series of ophthalmological clinics throughout the country was established to assist in the certification. Since 1945 the CNIB has insisted on an ophthalmological report as necessary for registration. All applicants for blindness allowances are automatically referred by the Government to the CNIB to determine whether they are already known to the Institute. It is estimated that the register covers approximately 95% of the blind people in Canada although there is no compulsory registration of the blind. However, a blind person must register with the Government in order to get blindness allowance. If he wishes to receive services from CNIB, he must register with that agency.

An IBM system was introduced 3 years ago in order to make register data more easily available.

Register data have helped in planning the over-all service programs, and in providing statistical data with which to approach the Federal Government, Community Chest, and the United Appeals which are sources of funds. A cause of blindness survey is under way in order to update a previous survey. Through such data the medical profession can be supplied with basic information needed for research projects.

- d. Dr. John W. Ferree, Executive Director, National Society for the Prevention of Blindness, presented a paper on "Blindness Statistics and the National Society for the Prevention of Blindness." (See Appendix D for this paper as well as discussion that followed.) This paper may be summarized as follows:

## SUMMARY:

The Model Reporting Area for Blindness Statistics is one of the most significant developments to date in getting precise information needed for more effective program planning and administration. The Society has for many years had an interest in the collection of better data referring to the problem of blindness, starting in 1908 with ways to apply knowledge concerning the prevention of ophthalmia neonatorum. The application of knowledge concerning the etiology of retrolental fibroplasia is revealed by the statistics showing the decrease in occurrence of this condition.

The Society's need for statistics is related to the need to define the problem better, that is to find out how many are blind and how many become blind each year by age groups and causes of blindness. Statistics are tools in epidemiological research to get at the causes of blindness and to study the natural history of the disease. Statistics are necessary for program evaluation and program orientation. More and better data are needed on the cost of care for the blind in order to justify increased funds for prevention activities.

Statistics derived from glaucoma screening programs have proven of value in defining the magnitude and nature of the problems of glaucoma. These screening programs consistently pick up about 2% of the surveyed population aged 40 years and over. In the United States an estimated 1,315,000 persons in this age range have glaucoma. Approximately half of this number are unaware of their condition.

The effects of an educational or service program can be measured statistically in terms of some objective criteria. This would give clues as to the effectiveness of such programs on the total population or sub-population, such as by age, sex, race, etc. Program orientation benefits from statistics that are derived from causes of blindness studies. For example, the infectious causes of blindness have decreased while there has been an increase in the causes associated with the aging of the population. Such statistics have significance for public education programs and for pinpointing those

population groups and areas that most need attention. This, in turn, acts to stimulate research where the need is greatest. For example, it is important that the increase in blindness due to diabetic retinopathy should result in stimulating research in this area.

The Society has been interested for a long time in the development and periodic revisions of a classification of causes of blindness. Efforts are being made to come out with an international classification usable throughout the world in order to get data eventually comparable from country to country.

Future prospects of the Model Reporting Area are bright, if the States in the Area support the effort to go ahead with what is planned for the Area, and if model reporting is extended to a significant number of States so that extrapolation to the rest of the country is feasible and proper.

The cooperation of the National Society will be available in every way possible. In turn, the Society will depend on each State for the kind of information needed to do more effective program planning in reference to prevention of blindness, and restoration and conservation of vision.

- e. Mr. M. Robert Barnett, Executive Director, American Foundation for the Blind, presented a paper on "The Importance of Uniform Reporting by Agencies for the Blind as Seen by the American Foundation for the Blind." (See Appendix E for this paper as well as discussion that followed.) This paper may be summarized as follows:

## SUMMARY:

In general, the American Foundation for the Blind endorses the principle of uniform reporting of blindness in the United States to get information relative to (1) incidence and prevalence of blindness, and (2) socially useful research and effective service planning. A uniform nomenclature should be used to pro-

Foundation does not believe compulsory registration of the blind is either necessary or desirable. In the past, State register efforts have been unsuccessful probably due to (a) lack of conviction that the register may be useful for planning, (b) belief that funds to maintain registers are disproportionately high in view of generally inadequate budgets for service, (c) lack of trained personnel for register maintenance, and (d) inability to set up and maintain efficient plans for cooperation with all sources of register information. The Foundation's consultants to local operating agencies have advised against efforts to initiate or continue register systems. However, the Foundation would alter this viewpoint if the Model Reporting Area evolves plans for uniform and useful data gathering systems on an efficient and economical basis. The term "register" should not be confused with the maintenance of a case record system of high caliber. Agencies should maintain good, uniform case records for uniform reporting and/or efficient use by researchers.

The Foundation's general attitude, as given above, is, in part, due to (a) awareness of absence of sound statistical information on blindness, (b) cooperation with other organizations to secure statistical data through census and population sampling, (c) awareness of conflicting philosophies of "list keeping" versus public fund expenditures and the psychological impact on individuals and social attitudes by such list keeping, and (d) a recent Foundation project to determine factors underlying the purpose, method and cost of a useful register.

The Foundation endorses as a minimum the essential data to be collected by the Model Reporting Area and urges that data on "near vision" also be included now, and possibly that data on educational and vocational status be included in the future.

The Foundation will (1) make available to the Model Reporting Area its register study findings, (2) coordinate community surveys now

(3) inform its field representatives of the Model Reporting Area program and urge their supportive consultation on field visits, and (4) where necessary, help in analysis and interpretation.

- f. Dr. Dana Quade, Biometrics Branch, National Institute of Neurological Diseases and Blindness, presented a paper on "The North Carolina Project." (See Appendix F for this paper as well as discussion that followed.) This paper may be summarized as follows:

#### SUMMARY:

The North Carolina State Commission for the Blind is at present maintaining a register of blind persons in that State. Reporting of blindness in North Carolina is mandatory, and, since excellent cooperation has been obtained from professional personnel and voluntary agencies throughout the State, the register is fairly complete. The procedures used for keeping the register up-to-date are excellent. Furthermore, considerable data are collected on each registrant. However, those data are recorded, without any coding, on 5x8 register cards which must be dealt with entirely by hand. There are now some 13,000 of these on file. Therefore, it is extremely difficult to extract useful data from the wealth of information which is present; indeed, for many years there have been only biennial counts including marginal totals by age, sex, and race but no cross-tabulations whatever. In view of this fact, the Biometrics Branch, National Institute of Neurological Diseases and Blindness, suggested the establishment of a punch card system for the register, but this would involve an initial expense beyond the means of the Commission. Therefore, a contract has been negotiated between the Commission and the National Institute of Neurological Diseases and Blindness under which the Public Health

Service will provide funds for the transfer to punch cards. This includes the hiring of temporary clerical help needed for coding the data, particularly the Standard Classification of the Causes of Blindness; transferring the data from the old register cards to new ones; the hiring of an outside agency to punch and verify the new statistical cards and tabulate them; and the cost of various supplies and materials. (The consultative services of the Biometrics Branch, National Institute of Neurological Diseases and Blindness, are, in addition, available, and are offered generally for the purposes of establishing registers or improving those already in existence.)

The work is to be done in two phases. The first phase, to be completed by July 1, 1962, involves setting up a new register card corresponding to each old one, with only name, register number, and date added to register recorded on it; sending the new cards to the district offices for completion (except for cause and degree of blindness) in connection with clearance of the register; and punching statistical cards from the new register cards. The second phase, to be begun in the fall of 1962 and completed by January 1, 1963, involves looking up the eye reports, coding cause and degree of blindness, and adding these items to the new register cards and statistical cards. Afterwards, the Commission will undertake to maintain the new system.

The register was originally set up as a special project of the WPA more than 25 years ago, representing a capital investment by the Federal Government at that time. Surely this new investment will also have a long-lasting beneficial effect in furthering the cause of good statistics on the blind.

g. Mr. Irving D. Goldberg, Biometrics Branch, National Institute of Neurological Diseases and Blindness, presented a paper on "Study of the Association Between Factors of Pregnancy, Labor and Delivery and the Occurrence of Blindness in Children in New York State." (See Appendix G for this paper as well as discussion

that followed.) This paper may be summarized as follows:

#### SUMMARY:

In a recent study by Miss C. Edith Kerby on the causes of blindness in children of school age, she found that blindness was presumed to be due to prenatal influence in 56% of the study group, of which 42% were due to unspecified prenatal causes and 14% presumed to be of genetic origin. An additional 7% were due apparently to undetermined causes. Miss Kerby pointed out that "factors affecting early development of the eyes constitute the most important problem in preventing blindness in children." In light of the apparent importance of prenatal and genetic factors as a cause of blindness in children, the Biometrics Branch, National Institute of Neurological Diseases and Blindness, thought it would be most desirable to look into the possibility of conducting research which might shed some light on this matter.

Since it was totally infeasible to conduct a prospective long-term followup study, a retrospective study was designed. Basically, the retrospective approach starts with a group of affected children born in New York State during a specified period of years. The birth certificates of these children are searched for information on complications of pregnancy and labor. Frequency of specific complications for the case group are then compared with that obtained from birth certificates of a control group composed of a representative sample of all recorded live births (surviving the first 28 days of life) in the State over the same time period.

The area chosen for the study was New York State for the following reasons:

1. The New York State Commission for the Blind had maintained a mandatory register since its inception in 1913, and the reporting of blind persons to the Commission became mandatory in 1945.

3. The New York State Commission had been employing the Standard Classification of the Causes of Blindness ever since its adoption in 1940, including the subsequent revisions of the Classification.
4. The legal definition of blindness in New York State was almost identical to that which was originally thought desirable for the study. The legal definition is as follows: "A blind person shall be defined as one who is totally blind or has impaired vision of not more than 20/200 visual acuity in the better eye and for whom a diagnosis and medical findings show that vision cannot be improved to better than 20/200; or who has loss of vision due wholly or in part to impairment of full vision or to other factors which affect the usefulness of vision to a like degree."
5. Birth certificates in New York City and Upstate New York contained the necessary information on specific complications of pregnancy and labor.
6. Cooperation from the New York State Commission for the Blind, and from the New York City and New York State Departments of Health, was assured.

The study objective is to determine whether mothers of blind children are characterized by an excess of selected prenatal and perinatal disorders as compared to mothers of the total population of live births surviving the neonatal period.

The study population consists of all children, approximately 500 cases, who meet the following criteria: (1) born during the period 1948-1960; (2) classified as "blind" by the New York State Commission for the Blind during the period 1948-1960; (3) having blindness presumed to be due to unspecified prenatal or genetic factors or to otherwise unknown factors; (4) having birth certificates on file at the New York City or the New York State Departments of Health; and (5) single-born. The control group consists of a stratified sample of 3 in

formation to be collected for both study cases and controls include date and county of birth, sex of child, weight at birth, race of mother, age of mother, number of previous children, specific complications of pregnancy and labor, operative procedures, Rh factor, presence or absence of congenital abnormality or birth injury. In addition, for cases only, information will be collected on cause of blindness and year classified as blind.

The analysis will consist of a comparison of cases and controls on factors mentioned above. Insofar as possible, different categories (type and site) of blindness will be studied separately.

At the present time information on cases has been obtained from the Commission, but the birth certificates of these cases have not yet been searched. Abstracting of data on controls is under way in New York City and will begin upstate in April 1962.

- b. Mr. Eugene Rogot, Biometrics Branch, National Institute of Neurological Diseases and Blindness, presented a paper on "Study of Survivorship and Causes of Death Among the Blind in Massachusetts." (See Appendix II for this paper as well as discussion that followed.) This paper may be summarized as follows:

#### SUMMARY:

There is very little statistical information now available on survivorship patterns or causes of death among the blind. The most recent study known of is one conducted by the Metropolitan Life Insurance Company during the period 1928 to 1933, which relates to the experience of some 11,000 policyholders who became blind.

As a group, it was found that the death rate of these blind policyholders was two and one-half times that of all policyholders. Results from this study were reported in the September

The present study is similar to the earlier one but has the advantage, it is believed, of relying on a less selective type of population. It is being conducted with the help and cooperation of the Massachusetts Division of the Blind and the Massachusetts Office of Vital Statistics. The study objectives are: first, to determine survival rates for blind persons by age, sex and cause of blindness, and compare with corresponding rates observed in the general population; and second, to determine the distribution of causes of death among blind persons by age, sex, and cause of blindness, and compare with corresponding distributions observed in the general population.

The study population consists of all persons first registered blind by the Massachusetts Division of the Blind between January 1, 1940 and December 31, 1959. The closing date for followup is December 31, 1961. This should provide about 12,000 blind persons, observed for differing periods of time up to 22 years from the date registered as blind.

It is estimated that some 5000 deaths will have occurred in the study group.

The definition of blindness to be used is the legal definition in Massachusetts and which is the Model Reporting Area definition, namely, corrected vision of 20/300 or less in the better eye, or peripheral field of vision contracted to 20° diameter or less, regardless of visual acuity.

Data collection began in January 1962. Information to be collected includes date of birth, sex, race, date of registration, visual acuity, cause of blindness, and underlying cause of death.

1. Mr. Irving Goldberg, Biometrics Branch, National Institute of Neurological Diseases and Blindness, presented a paper on "The Need for Good Statistics on the Blind." (See Appendix I for this paper as well as discussion that followed). This paper may be summarized as follows:

#### SUMMARY:

The importance of accurate and uniform statistics on the blind has, in the past, been expressed by various individuals concerned with the problem of blindness. It is evident that the need for good statistics on the blind is basic to all interested agencies: official or voluntary; local, State, Federal or international; and to all interested professional and lay groups as well.

Since the efforts of the Model Reporting Area to obtain these needed data rely on blindness registers as their source, Mr. Goldberg commented on the function of a well-organized register. A good register of the blind should serve a dual function: (a) to enhance the administration of a service program, and (b) to provide statistical information, not only for planning and evaluation of the service program, but for determining the magnitude and nature of the blindness problem. In Mr. Goldberg's opinion, a register which serves one of these two purposes without the other results in the loss of valuable potential in the prevention, control and treatment of blindness.

Mr. Goldberg then turned to the various needs served by an adequate up-to-date register. In this regard, he noted that the needs of the many interested agencies and groups cannot all be satisfied without uniformly and accurately collected data based on a uniform definition of blindness. The needs were grouped into two broad categories: (a) administrative and service, and (b) research.

The administrative and service needs served by registers were indicated as follows:

1. A register can be useful in pinpointing specific hazards that cause blindness, and thus help to promote legislation for the control of such hazards as well as to set up programs of education, prevention, and control.
2. It is useful in determining trends in caseloads and, hence, in projecting the type and number of staff needed by the agency; in justifying budget needs, and in estimating the future need for educational and other various facilities.

and emphasis.

4. It provides statistics to show, by geographic subdivision, the number of cases on the register as well as accessions to and removals from the register on a periodic basis. Such data are helpful in pinpointing areas of high incidence or prevalence and determining the need for intensive case finding or preventive programs.
5. It provides descriptive statistics of the population served, such as by age, sex, race, cause of blindness, degree of vision, etc., for inclusion in annual and other periodic reports, for the entire program or for special programs.
6. It is useful in public relations by providing information for presentation to various lay and professional groups, indicating the magnitude of the problem in their respective communities.
7. It is useful in answering requests from individuals and from public, private, and voluntary agencies for information on the magnitude of the problem by county, age, sex, cause of blindness, etc.
8. It is useful in providing specific information quickly to appropriate public and voluntary agencies, relating to an individual's blindness status, services received, etc.
9. It is useful as a case-control mechanism in determining whether individuals referred for service have previously been registered, and what specific information is available.
10. It is useful in maintaining a record of services given over specified time periods, and in determining what proportion of the blind are receiving the various specified types of service.
11. It is useful in relating services to characteristics of individuals served.

The research needs served by an adequate up-to-date register were summarized by Mr. Goldberg by referring to a number of such studies now being planned, already under way, or which have been completed.

mentioned needs, Mr. Goldberg pointed out that the Area is founded on the concept that reliable, meaningful statistics, comparable from State to State, are urgently needed. It is hoped that through the cooperation of member States in agreeing to uniform definitions and standards this objective will be achieved. It is believed that administrative, service, and research needs will be served by data collected by the Model Reporting Area States to a far greater degree than is now possible.

### III. REVIEW OF STANDARDS FOR MEMBERSHIP IN THE MODEL REPORTING AREA FOR BLINDNESS STATISTICS

Irving D. Goldberg, Biometrics Branch, National Institute of Neurological Diseases and Blindness

Mr. Goldberg opened his comments by referring to the "Proposed Standards for Admission to the Model Reporting Area for Blindness Statistics" which was included in the packet provided to the participants. He noted that the statement of the Standards was approved by the Planning Group in September 1961, and had been accepted in substance by the Model Reporting Area States through questionnaire and on visits by the Biometrics Branch staff to the States.

Mr. Goldberg stated that a number of questions and suggestions were made relating to the standards since their original preparation, and that these observations would be presented in the course of his discussion. Also, he noted that the "Proposed Standards," as they were originally prepared, included a number of recommendations which were not standards, as such, but which were included for orientation and explanatory purposes. Such recommendations would be excluded from the final statement of Standards for Admission to the Model Reporting Area. Also, based on decisions reached at the Conference, the standards would

be revised and copies would be sent to member States.

Before presenting the standards, Mr. Goldberg invited the participants to ask any questions or make any comments during the course of his presentation.

Mr. Goldberg read each section of the "Proposed Standards for Admission to the Model Reporting Area for Blindness Statistics," explained the contents of each section, and brought to the attention of the participants certain questions which were raised after the standards were originally proposed. Mr. Goldberg's comments and the ensuing discussion follow.

### Section I - Definition of Blindness

"For Model Reporting Area for Blindness Statistics purposes the data to be collected and submitted annually in summary form to the NINDB for tabulation, analysis, and publication will be based on a common definition of blindness. Most States use, at least for Aid to Blind and Vocational Rehabilitation Services, the definition based on visual acuity of 20/200 in the better eye with best correction or a limitation in the field of vision such that the widest diameter of the visual field subtends an angle no greater than 20 degrees. This will not include persons with a progressive eye condition who do not yet meet the definition requirements mentioned above. A State must be able to identify and isolate those cases meeting this standard definition. It is proposed, for purposes of comparability and poolability, that only data on cases meeting the requirements of the standard definition be reported to the NINDB annually."

On visits to various States a question was raised regarding the interpretation of "best correction" in the Model Reporting Area definition of blindness. Mr. Goldberg pointed out that this was interpreted to mean best "normal" correction and would not include low vision aids.

Mr. Meyer asked if any analysis had ever been made to determine whether it was possible for low vision aids to improve central visual acuity to better than 20/200 without restricting the field of vision to such an extent that the individual would be classified blind under the visual field criteria. He thought that contact lenses might fall in this category, but by the same token it would be a question whether an individual ought to be considered blind if he gained reasonably normal vision with contact lenses. Mr. Meyer wondered if a review of cases who have been given increased usable vision by special lenses would not show that the individuals were still within the definition on the basis of limited field. Although he did not consider himself an expert on low-vision lenses, Mr. Meyer could not conceive of a low-vision lens being fitted to an individual so as to bring his vision superior to the scale where he would normally be considered blind, under the limited field area. Most of the processes used in fitting lenses to individuals with a small amount of vision make that vision of practical use to them, but they do not actually increase the amount of vision which the individuals have.

Mr. Goldberg asked if Mr. Meyer's remarks meant low vision aids would not really be a problem in the definition; but Mr. Meyer said he would like to have somebody more knowledgeable than himself on this matter say that.

Mr. Barnett asked if, by definition, a person could have corrected vision to 20/20 and still be classified blind. Mr. Goldberg stated this would be possible according to the visual field criteria.

Dr. Hurlin referred to section II of the "Standards" which states that field of vision restriction need not be recorded if visual acuity is 20/200 or less. He thought this was pertinent regarding Mr. Meyer's comments that a person, fitted with the special gun-barrel or rifle lenses which give point vision, may have improved visual acuity so that he doesn't meet the definition. Mr. Goldberg stated that information on field restriction would be necessary for a person with corrected acuity better than 20/200 to be considered blind. Thus, if strong lenses restricted the visual field to 20 degrees or less,



Miss Anderson commented on the need for some clarification of what constitutes visual aids, since some persons might be able to use contact lenses only for limited periods of time so that such lenses might serve only as visual aids; whereas other individuals may be able to tolerate contact lenses all day long.

Mr. Meyer mentioned that it is extremely difficult to obtain field of vision information, and hence it is one of the big problems. Mr. Goldberg stated that this gets down to the basic issue of good reporting, not only for degree of vision, but for other items as well, such as cause of blindness. He noted that some effort is necessary to improve reporting of cases and items of information, and he expressed the hope that the Model Reporting Area would serve as the instrument to stimulate better reporting.

Mr. Goldberg noted that the States may employ a broader definition than the Model Reporting Area definition, but cases classified as blind according to the Model Reporting Area definition would have to be distinguished from those classified blind according to the broader definition. Thus, in such cases, a State would have in effect two registers: a "total State register" of which a segment is the "Model Reporting Area register."

Another question brought to Mr. Goldberg's attention over the past several months pertained to the classification as blind of very young children or very old individuals on whom it is not possible to obtain a good examination. In such instances the opinion of the examining ophthalmologist, or the best opinion that can otherwise be obtained, should be used. Thus, if the examining ophthalmologist considers a very young child to be blind, although he cannot determine the precise visual acuity, his opinion should be accepted.

It was agreed to accept the definition of blindness as presented along with clarification of the questions raised in the discussion.

"The register of persons, considered blind under the above standard definition, which is maintained by a State admitted to the Model Reporting Area for Blindness Statistics shall include cases of all ages. There shall be no exclusion based on age."

Mr. Goldberg noted that although this section states "there shall be no exclusion based on age," actually it implies that there shall be no exclusion from the Model Reporting Area register for any reason other than not meeting the definition of blindness. Thus, there would be no arbitrary exclusions due to lack of need for service, race, residence in institutions, or any other factor outside of the definition.

### Section 3 - Essential Items of Information

"Data to be collected for Model Reporting Area for Blindness Statistics purposes must include at least the items indicated below. When reports are received by the State that are incomplete or ambiguous, attempts must be made to get missing data or clarification. The following items must appear on their register card so that abstracting such information does not involve searching case folders, etc. There is no restriction on other items of information that a State may wish to collect for its own information.

- A. Date of addition to the register of cases with the standard definition
- B. County of residence
- C. Date of birth
- D. Sex

E. Race (except where prohibited by state legal requirement)

F. Age at loss of sight

G. Classification (site and etiology) using the Standard Classification of the Causes of Blindness. Where a State is not presently using the Standard Classification of Causes of Blindness but is otherwise eligible for membership in the Model Reporting Area for Blindness Statistics, it is recommended that such State be admitted to the Area contingent upon installing or making the transition to the Standard Classification within three years after admission. Eligible States that are currently using the 1940 or 1957 Standard Classification must be able to relate their classification to the latest (1960) Standard Classification.

H. Visual acuity (specified) and field of vision restriction (specified). However, where visual acuity is 20/200 or less in the better eye with best correction, it would be permissible to omit information on field of vision restriction.

I. Date of removal from register.

J. Reason for removal from register, such as death, restoration of vision beyond eligibility under the standard definition, moved out of State, or unable to locate."

A. Date of Addition to the Model Reporting Area Register (i.e. of persons meeting the standard definition).

Mr. Goldberg asked if it would be agreeable to subdivide this information into two groups: (a) date of first addition to the Model Reporting Area register, representing persons not known to the register previously, and (b) date of readmission to the register, representing persons added to the register who were previously on the Model Reporting Area register but were removed for some reason such as restoration of sight after cataract removal.

Mr. Meyer noted that most agencies think of readmissions in terms of persons crossing State boundaries and that these amount to a considerable number. He raised a question as to how we would be able to distinguish between readmissions because of migration across State lines as distinct from readmissions because persons have again lost their sight after it was once restored. Mr. Goldberg pointed out that information on reason for removal, as well as date of removal, would be among the required items, and from this information it would be possible to determine the basis for classifying a person as a readmission. Mr. Meyer also raised some question about administrative feasibility in determining whether a person is a first addition or a readmission, as in the case of an individual who may have left the State say 15 years ago. Mr. Goldberg noted that at present the States are limited by the nature of their existing registers. Where the registers have been well maintained and the records have not been destroyed, identification of the individual as a readmission should not be a particularly difficult problem. This may be even simplified where a State has been employing a unit case numbering system. After a check against the files, if a person is found to be a readmission this would be recorded so that, in the statistics, it will be possible to distinguish between individuals not known to be

At this point Mr. Goldberg mentioned that the required items were arrived at after considering what was desirable to collect and what was feasible for the States to obtain. He also stressed that it is necessary for each of the required items to appear on the register card or its equivalent.

blind before, and those previously known to be blind.

It was agreed that separation of additions to the register into first additions and readmissions would be feasible.

#### B. County of Residence

Mr. Goldberg noted that this item was included by the Planning Group, because information by county would be of value to the States themselves and would provide helpful information on the geographic distribution of blindness. Subdivision of counties by towns would satisfy this requirement.

#### C. Date of Birth (no discussion)

#### D. Sex (no discussion)

#### E. Race

This item would not be required if prohibited by State legislation. It was agreed that subdivision into White, Negro, Indian, and Other would be feasible.

#### F. Age at Loss of Sight

Mr. Goldberg stated that while the Planning Group was aware that this item would be very difficult to obtain accurately, it was, nevertheless, very desirable to obtain. Consequently, it was included as a required item in hope that the Model Reporting Area might stimulate better reporting, and that a more conscientious effort would be made to obtain this information over the next few years.

Miss Cole asked whether this is meant to be the age at which the individual himself thinks he has begun to lose his sight, or the age at which the doctor says he became legally blind. Mr. Goldberg thought the statement of

the individual could not be ignored and that the physician would have to rely, at least in part, on information given to him by the individual; and that all available information should be used in arriving at the determination. The aim was to obtain an approximate date when the person first became blind within the Model Reporting Area definition. In only a limited number of instances, such as in the event of accident resulting in total loss of sight, will it be possible to determine precisely the age at which the person lost his sight. This item is not meant to indicate the onset of the condition which led to blindness, but rather the age at which the person actually became blind.

Mr. Meyer thought it would be helpful to know how this information was to be used, and whether the criteria of 20/200 was a major consideration. Mr. Goldberg indicated that in the census enumerations of the blind, attempts had been made to obtain such information. He pointed out that this information would be helpful in determining the age at which the population is subject to the risk of blindness, and hence, would be beneficial in terms of prevention programs. He noted that there may be an appreciable number of years between age at loss of sight and age at registration. Also, such data would be of value in research such as the patterns of survivorship among the blind from the time of onset as distinct from registration. The best that could be done, except in cases where there is a sudden total loss of sight, is to obtain the approximate age when the person became blind within the definition.

Dr. Hurlin stated that he had been doing a lot of work on the reporting form that the physician uses, and his personal opinion is that the form should ask for the probable age at loss of sight. The ophthalmologist should not be asked to say at what age the person loses sight to the degree specified in the definition, but he should be asked to state what in his opinion is the probable age at which the person had serious impairment. Dr. Hurlin also commented on the reason this information is needed, pointing out that such data are desirable in connection with incidence. It is hoped that registers will provide data on blindness incidence.

However, people coming from another State may have been blind since childhood, but are not registered until after such migration. Information on age at loss of sight would help to take this factor into account in the determination of incidence.

Dr. Goldstein agreed with Dr. Hurlin, adding that ordinary incidence rates, by age and other factors, relate to cases that become known to an agency for the first time although a given case may have been blind for 20 or 30 years before he was put on the register. Thus, information on age at loss of sight would be one way of getting such data as onset rates by age or other factors.

Miss Cole suggested that the term "onset" was preferable to "age at loss of sight." Mr. Goldberg stated that the latter term was used partly because the term "onset" has been misinterpreted in some States to indicate the onset of the condition which led to blindness.

Mr. Meyer thought it was important to define the concept that one is to have in mind, because very largely the question is going to be answered by the individual. The more one thinks about it, the more the question arises as to whether the precise visual acuity at the time an individual became an economic or social problem is as important as the question of when the trouble really came about. The individual was going to be guided by when the condition affected his living processes and working, etc.

Miss Cole noted that some individuals with vision as low as 5/200 do not consider themselves blind. She said that what one wants to know is when the individual first knew he was losing his sight, and that the word "onset" is more descriptive of this than "loss of sight."

Additional discussion took place regarding whether the determination is to be made by the physician or by the individual. Mr. Meyer stated, in reference to Miss Cole's comment, that while the individual may not consider himself blind, the physician might and it is the physician who is answering the question. Miss Cole stated that the physician will be answering the question by asking the individual, "When did you first notice this eye trouble coming on?" Dr. Hurlin stated that the physician would render

his opinion, regardless of what the patient says, if the reporting form is designed so as to tell the physician what is wanted. Miss Cole thought there would then be two opinions, the physician's and the patient's, and the latter should be taken. Dr. Hurlin felt the physician's opinion is the one which is desired.

In light of some difference of opinion regarding the definition and interpretation of the term "age at loss of sight," Mr. Goldberg suggested that the final determination be left to the Planning Group with representation of the States. It was agreed that the item would be maintained and, as suggested by Miss Anderson, that it would be worded in language clear to the physician and layman.

#### G. Standard Classification of the Causes of Blindness

Mr. Goldberg stated that detailed discussion of this item would be deferred until the following day when Dr. Hurlin and Mrs. Hatfield were to present the current status of the Standard Classification of the Causes of Blindness. However, he pointed out that all appropriate agency personnel would be trained in the use of the classification, and that the purpose was to have each State employ a single standard classification.

The participants agreed to adopt the latest revision of the standard classification. It will be used immediately after appropriate training to State staff for all new cases reported to registers, and will be adopted for all existing cases in the register within three years after securing membership in the Area.

#### H. Visual Acuity

Mr. Goldberg stated that the suggestion made in Mr. Barnett's presenta-

tion (Appendix E) relating to inclusion of near vision, might be considered by the member States and the Planning Group. He also indicated that where an individual is classified blind by reason of limitation of the visual field, the field of vision restriction should be recorded on the register card. In addition, the central visual acuity must be available in the case record, and is to be recorded on the register card precisely or at least according to the Model Reporting Area vision grouping.

- I. Date of Removal from Register (no discussion)
- J. Reason for Removal from Register (no discussion)

#### Section 4 - Desired, But Not Required, Items

"The following items, though not essential for membership in the Model Reporting Area for Blindness Statistics, are recommended. The ability and wishes of the Area members to furnish these and other items of information would largely determine the desirability of preparing tabulations for such items:

- A. Presence or absence of eye examination report
- B. Discipline of eye examiner, such as ophthalmologist, optometrist, physician, other
- C. Date of last eye examination report
- D. Source of referral
- E. Education

#### F. Occupation before blindness

#### G. Age at first diagnosis

#### H. Presence or absence of physical examination

#### I. Specific handicaps and medical conditions (grouped)

#### J. Date of first classification of blindness under the standard definition of blindness."

Mr. Goldberg pointed out that although a number of items of information would be highly desirable, they were not included under the required items because of the question of feasibility. Of the desirable, but not required, items listed in the "Proposed Standards," he explained that the item "presence or absence of eye examination report" was meant to be interpreted as presence or absence of a professional examination. In addition, he mentioned a number of other items which might be of interest including marital status, residence in institutions, a register unit number, removal history, and services provided to the individual, such as Aid to the Blind, vocational rehabilitation, and talking books.

Mr. Goldberg observed that, hopefully, the member States might consider making some of these items part of the standards for membership when they feel it is feasible to do so. Until such time, however, it would be helpful to obtain tabulations on certain of these items from those States that can now provide them.

#### Section 5 - Updating the Register

"To be eligible for membership in the Model Reporting Area for Blindness Statistics a State must continuously update the status of persons on the register using any and all reliable information available on such

persons. For persons who are either not receiving services or are not contacted periodically by staff of the blindness agency, it is, in addition, necessary that the agency make concerted efforts to institute or to continue periodic contacts at least annually by mail or otherwise."

Mr. Goldberg mentioned that the purpose of this standard is to keep the registers up-to-date so that good prevalence data may be obtained.

Mr. Barnett brought out some experience of the American Foundation for the Blind concerning registers that have failed in the past. In such cases a good job was usually done after an initial, one-time, stimulus, but the problem of maintenance was found to be difficult. Mr. Goldberg pointed out that this matter was of primary interest to the Model Reporting Area, and that each of the member States has now in process or will have in process a procedure which will enable it to keep its register up-to-date. Furthermore, this will be looked into very closely as a continuing problem of the Model Reporting Area. He also stated that certain materials will be distributed to the various States, and among these materials will be the procedures used by all of the member States on the ways in which they update their registers, so that each member might benefit from experience of the others.

With regard to updating procedures, Mr. Goldberg indicated that contacts do not necessarily have to be made with individuals, as such, in certain instances; for example, where an agency maintaining a blindness register does not provide a particular service to blind individuals, but such service is provided by another agency of the State, then it would be sufficient for the agency maintaining the register to contact the other agency providing the service to determine the actual status of the individuals.

In passing, Mr. Goldberg referred to the term "register prevalence" and explained that due to underreporting and other factors, prevalence statistics based on the register may not truly reflect the actual prevalence of blindness in the population at large. Hence, the term "register prevalence" is used. Similarly, ac-

cessions to the register ("register incidence") may not precisely reflect the true incidence of blindness in the population.

## Section 6 - Maintenance of Standards

"To be eligible for membership in Model Reporting Area for Blindness Statistics, a State must agree to observe the standards for membership set up by the Model Reporting Area for Blindness Statistics as well as to complete and forward to NINDB the required annual summary tabulations. It is further agreed that membership will continue as long as the standards are observed. It is recommended that the Model Reporting Area for Blindness Statistics set up procedures to make periodic evaluations of the data submitted in order to ensure maintenance at the minimum standards."

Mr. Goldberg stated that continuing evaluations of adherence to the standards will be made by the Biometrics Branch to insure that data derived from the Model Reporting Area are based on and satisfy the standards that were set up, and to be sure of the comparability of information from State to State.

## Section 7 - Annual Tabulations

"In view of the fact that estimated populations are usually as of July 1 of a given year, it is recommended that, if possible, calendar year data be submitted by the States to NINDB."

Mr. Goldberg mentioned the desirability of having all tabulations prepared on a calendar year basis. He stated that on visits to the various States, the Biometrics Branch found that most, if not all, States can provide calendar year data. Where States could provide data only on a fiscal year basis, special consideration may have to be given.

All participants indicated that data could be provided on a calendar year basis. Mr. Goldberg

stated that the Biometrics Branch, in the absence of any firm guidelines, arbitrarily set March 15 as the date by which each State must submit its tabulations for the previous year to the National Institute of Neurological Diseases and Blindness. This date was agreeable to all member States.

Mr. Goldberg noted that the Biometrics Branch will be able to provide assistance, where necessary, to States in preparing their tabulations for the current year. However, in the future, it was expected that States would staff themselves and be oriented enough to prepare data on their own. As the Model Reporting Area grows in size it would become increasingly difficult to provide much help to the various States in the preparation of the tabulations. Furthermore, if a State is to function fully in the Model Reporting Area, it should make every effort to obtain these data and prepare tabulations with its own staff.

#### Section 8 - Use of Mechanical Equipment

"Although the use of mechanical (such as IBM) or other types of data processing equipment (such as McBee) is not considered essential for membership in the Model Reporting Area for Blindness Statistics, the adoption of such types of equipment for processing data in States with sufficient volume should be encouraged in order to (1) reduce errors in tabulating; (2) to facilitate the production of tabulations, and (3) make it possible to exploit the data collected to a greater degree with little, if any, increase in staff."

Mr. Goldberg stated that he would not comment on the advantages of mechanical equipment in the maintenance of a register and preparation of tabulations since this was scheduled for discussion by Dr. Quade on the following day.

Mr. Goldberg then outlined briefly the procedures that would be used in amending the Standards for membership. The procedures, which will be specified in the final statement

of the Standards, are basically as follows: A request would be received from a member State for a specific amendment to the Standards, which would be reviewed by all other member States, and eventually considered for approval by the Planning Group.

The procedures for admission of a State to the Model Reporting Area were summarized. A State requesting admission to the Area must subscribe to the objectives, request admission to the Area, and must meet the minimum standards to the satisfaction of the Biometrics Branch with the approval of the Planning Group. Also, where there is a time interval for adoption of certain particular standards, such as the Standard Classification of the Causes of Blindness, the admitted State must comply with this requirement within the time limitation.

Mr. Goldberg concluded his remarks with a statement on the maintenance of records. He indicated that all records should be maintained at least three years as a bare minimum, following preparation of tabulations from such records. He stated, further, that it would be desirable for all records to be kept for as long as State policies permit.

Miss Cole stated that she took exception to Mr. Barnett's suggestion that near vision be included as one of the standards. To this point, Dr. Goldstein indicated that the member States would be canvassed for their opinions and pertinent comments on that matter, and this procedure would be true for any standards to be added or amended.

Dr. Goldstein also commented on several other points raised during Mr. Goldberg's presentation of the standards. He stated that when Mr. Goldberg mentioned the date of addition or readmission to the register, it should be remembered that he meant addition to the Model Reporting Area register. This is important, particularly in any State where the definition of blindness is broader than the one adopted for the Model Reporting Area. With reference to the question raised by Mr. Meyer regarding transit from State to State, Dr. Goldstein stated that this was an important question but, until a national register is achieved which includes all 50 States, it would be impossible to do much

about it. Finally, with regard to the question of how one determines whether a person had previously been registered, Dr. Goldstein emphasized that it was important that records not be destroyed too soon. Thus, when the records are available from the past there are different ways of screening to see whether the individual who has been reported was previously known to the register, utilizing such information as Soundex, date of birth, and other pertinent data that make it possible to identify an individual fairly reliably.

#### IV. REGISTER PROBLEMS IN THE MODEL REPORTING AREA STATES AND HOW THEY WILL BE MET

**CONNECTICUT:** Mr. McCollam indicated that the problems in Connecticut were not greatly different from those already touched upon during the meeting. At first the idea of preparing tabulations from some 3600 McBee cards, which comprise the blindness register, seemed to be a huge task. However, this task has been eased by the fact that the State of Connecticut is making available to smaller agencies and Departments, such as the Board of Education of the Blind, IBM data processing services. This conversion, however, would require a little time, possibly three months or more. Another problem was the lack of standard criteria to follow in reporting and gathering of the data to be asked for under the reporting system. The eye examination report form has been revised from time to time so as to be sure to incorporate all the data that would be needed to complete the statistical forms to be followed. An important problem is concerned with getting the cooperation of the ophthalmologists to furnish the kinds of data that are necessary. The National Institute of Neurological Diseases and Blindness might be helpful in devising a program for the information of ophthalmologists so that they would have a better picture of what is involved in statistical data gathering and so that they would, in time, be more amenable to giving the kinds of data required. Often

a report form is sent in by an ophthalmologist with very little information which can be coded. Even the State's consulting ophthalmologists, in reviewing such reports, have considerable difficulty in determining what is intended by the data in the report. In Connecticut the ophthalmologists and members of the Board staff responsible for register maintenance will need training in order to know how to interpret properly the data on the report forms.

In the past there had not been a very accurate method of updating the register. At present, however, attempts are being made to contact by mail all those on the register who have not received any service in the past six months. This will be repeated every six months to keep the register up to date.

**DELAWARE:** According to Dr. Cummings, Connecticut's problems also apply to Delaware. The records are in fairly good shape after many years of effort. An eye report from an ophthalmologist is received on every client. All persons on the register are visited at least once a year and many are visited more often than that. When there is the slightest indication that there might be a change in the eye situation, the client is referred to an ophthalmologist for an additional examination. The examination reports are reasonably complete depending on which ophthalmologist does the examination. Some ophthalmologists are busier than others. Although this might explain why some reports are poorer than others, Dr. Cummings believed that ophthalmologists are paid to do a job and they ought to do it. The eye examination form which has been approved by the Federal Government is not difficult to fill out. However, with the help of the consulting ophthalmologist who works wholeheartedly for the State program and who applies some pressure on his colleagues for better reports, Delaware, in Dr. Cummings' opinion, has been getting very good reports and very good data. At least the data seem to be complete and fulfill their purpose.

Delaware is very enthusiastic about the prospects of the Model Reporting Area system. It will give the State an opportunity of building



up more completely. It will also enable one to know what the situation about the blind in America really is.

**HAWAII:** Although Hawaii had been unable to send representatives to the Conference because of pressure of legislative activities there, Mr. Lawrence K. Nakatsuka, Interim Director of the Hawaii Department of Social Services, in a letter to the Chief, Biometrics Branch, National Institute of Neurological Diseases and Blindness, stated that anticipated problems included:

1. "Translation of causes of blindness to the 1960 standard classification. This is a problem of time rather than one of understanding.
2. "Annual contact with all persons registered. If other States have more effective means than those employed in Hawaii — that is, through invitations to annual events — Hawaii would appreciate knowing what they are."

**KANSAS:** Mr. Grabhorn stated that, in his opinion, the Kansas Division of Services for the Blind (a part of the State Department of Social Welfare), has a very complete register of blind persons which complies very well with the Model Reporting Area standards. Although it started as a service register, its usefulness extends beyond that point. The first problem of the agency was in locating blind people who needed service. The register thus began as a listing of clients who had been served or were being served. A directive of the State Board of Social Welfare stated that the county departments of welfare should call upon the blind at least once a year to explain the services available through the county departments or the Division. This way of serving the known blind population and, incidentally, of finding new blind persons to be served, was supplemented in 1949 by a law passed by the State legislature requiring social and health agencies and physicians to report to the Board of Health those people who became known to them as

blind persons. This resulted in the addition of many names to the register. Subsequent to 1949, another law was passed requiring vision screening of school children at least every two years. This, too, added many names to the register. Furthermore, county assessors in the course of their work would inquire for the names of known blind people and, thus, add still more names to the register. In general, more names are added to the register than removed from it. As of December 31, 1961, there was 8,194 persons registered.

Originally the client himself or some social agency or civic organization had to pay for the eye examination, unless he was a recipient of public assistance, in which case the county paid for it. However, the State Board of Social Welfare has approved a plan whereby the State Department of Social Welfare can and will pay for eye examinations for anyone presumed to be blind, whether or not he is applying for service. This would bring about the registration with complete medical information of additional people who might previously have been known to be blind but who would not be registered because of lack of medical information. In recent years an eye examination has been required for registration. Some of the register cards of persons reported in the early days of registration may not have complete medical information.

The responsibility of updating register information rests largely with the county social workers who are the main contact with blind people throughout the State. As mentioned above, a State Board directive required that every blind person be called upon at least once a year regardless of whether he was receiving services. Only this year have there been any exceptions to this annual visit rule. If a blind person has made an adequate adjustment, and is well aware of the services available to blind persons in Kansas, this is recognized as a good reason for not calling upon that particular person. This reason, however, has to be reported by the county social worker on a special form that requests certain additional information. There may be other reasons for not calling upon a blind person, according to Mr. Grabhorn, but it is required that, in every case where the

call is discussed, the social worker evaluate the situation and advise the Division which is ultimately responsible for the administration of the total program and services.

The Kansas register is on an IBM system which is operated by the Division of Research and Statistics of the Kansas Department of Social Welfare.

The register has not been put to much use although it was originally intended for use in program planning and as a device to provide information for services. However, recently the register was used in a study to determine how many registered blind persons also had driver's licenses. The Division, the Kansas Motor Vehicle Department, the Highway Patrol, and the Safety Division of the Highway Department are all interested in a stronger driver licensing bill to include vision screening. This bill has not as yet been passed by the State Legislature. The bill, if passed, would be very worthwhile in case finding. Many people who are blind but don't know that they are blind might very well be served in having a restricted driver's license or no driver's license at all. In Kansas any blind person who objects to being registered does not have to be registered. It is conceivable that a blind person would receive services and yet not be registered if he objected to such registration.

**LOUISIANA:** According to Mr. Bridges, there is some problem in obtaining information from physicians and optometrists. However, the big problem centers about the fact that the register, which is on an IBM basis, is not being updated. An attempt will be made to identify on the punch cards the active cases getting service of any type from those not getting it. This will depend on getting the cooperation of other agencies serving the blind. Mr. Bridges was of the opinion that this could be accomplished and, if so, it would facilitate the updating process. Among the agencies mentioned were the two Louisiana schools for the blind, State Department of Special Education, OASI, U. S. Public Health Leprosarium at Carville, Louisiana, and Louisiana Retirement System. Furthermore, an exchange of information among agencies

would also serve as a case finding mechanism. He also anticipated sending letters periodically to blind persons not getting services in order to bring to their attention the availability of such services. When such letters go unanswered he would arrange for visits to be made. Persons that could not be located would be removed from the register.

Mr. Bridges believed that the Model Reporting Area would be a means to help improve relationships of the Bureau with the ophthalmologists and optometrists. He indicated that recently when he informed some optometrists about the Model Reporting Area and the need for certain types of data, they were enthusiastic about this development and wanted to cooperate. He plans to address a State Meeting of optometrists in the fall and again bring up the need for certain types of information and for referral of blind cases. Furthermore, he plans to do the same thing at the next meeting of the State Academy of Ophthalmology. Efforts are also being made to have the Tulane University and Louisiana State University Departments of Ophthalmology inform their students about the need for reporting blind persons.

The Louisiana Department of Public Safety has agreed to report to the Bureau for the Blind and Sight Conservation the names of applicants for driver's licenses who are found to be legally blind.

The Louisiana Commissioner of Public Welfare has endorsed the concept of a Model Reporting Area for Blindness Statistics and will support Mr. Bridges in his efforts to improve the register.

**MASSACHUSETTS:** Mr. Mungovan stated that of the 8,400 blind on the Massachusetts register, almost half of them are receiving some direct service from the Division of the Blind. Therefore, an annual mail updating involves sending letters to some 4,700 people. The institutional blind population in Massachusetts, approximately a thousand persons, is updated by direct contact with the institutions. The items that the Model Reporting Area is going to tabulate, as well as the service information, are kept pretty well up-to-date. However, this

is not the case with data on social characteristics.

The service data were recently tabulated. It was found that only a small percent of the registered blind between the ages of 20 and 60 are referred for vocational rehabilitation. As a result, a procedure has been set up within the agency to give special attention to this age group with a view to referral for vocational rehabilitation. This is one of the uses made of the register.

Although it would be difficult to bring up-to-date all the items on the register, it can be done on a sample, such as 20% of the total register. Updating all items would require staff time that is not available. It would involve the Social Service staff and Vocational Rehabilitation staff which are already very busy. He did not want the extra work involved in improving the statistics to diminish services to the people.

Requests for certain types of information on age and sex characteristics of the blind, as well as on causes of blindness, are received quite often.

Preparation of tabulations for the Model Reporting Area would not be troublesome. However, Mr. Mungovan did not plan to tabulate very often for political subdivisions, such as towns and cities.

The register and its data are considered highly confidential. He stated that the possession of a driver's license would make a blind person ineligible for services.

He stressed the difficulty involved in changing statistical codes. It would not be possible to change every register card every time the code changed. Rather he would plan to change the code on the 10% of the cases that "turn over" each year. However, he did not know whether the 10% turned over in a year are 10% of the caseload or what percent they are of the people registered this year or the year before, etc.

In conclusion, Mr. Mungovan mentioned a 10-year followup study of blind persons registered in fiscal 1960 in order to determine survivorship, need for services, etc.

**NEW HAMPSHIRE:** Due to illness and pressure of work, New Hampshire had been unable to send representatives to the Conference. However, Mr. Carl Camp, Supervisor, Division of Blind Services, New Hampshire Department of Public Welfare, transmitted the following by mail to the Chief, Biometrics Branch, National Institute of Neurological Diseases and Blindness.

"The strength of our register has been born of and sustained by the dedication and cooperation of the ophthalmologists in New Hampshire and adjacent states. With their increased understanding and continued dependable service, we will overcome the isolated instances of obstacles which still persist.

"There is still some evidence of a natural reluctance on the part of some doctors to complete Physicians Eye Report forms even after a thorough examination may have been made, possibly because of more pressing demands on their time. In some instances where eye reports have been completed by willing and well-meaning doctors, the reports are somewhat wanting in the manner in which they are made out. Furthermore, eye doctors seem to be reluctant to commit themselves as to the date of onset of blindness unless they happen to be directly involved with the patient at the time of onset.

"Where eye reports have been on file for sometime without a re-examination, the visual acuity is apt to become outdated because of changing vision, especially in the aged blind population. Periodic re-examination is a sound goal toward which to strive though it is imbued with many problems such as availability of doctors, willingness or health of clients, expense and agency staff time.

"Another factor tending to detract from the effectiveness of a register is the in-

ability of doctors to properly give visual acuity on children because of their youth and other physical and mental handicaps.

"Still another factor affecting the register is the reluctance of some clients to undergo an examination or obtain an eye report if they have had an eye examination.

"Clients also move within or out of state without reporting this to the agency."

**NEW JERSEY:** Mr. Meyer indicated that the register of the New Jersey Commission for the Blind has been on an IBM system since 1955. A big problem is the followup on cases that have received service but no longer do so. Originally the intention was to visit such persons once every two or three years. Membership in the Model Reporting Area may help to reduce that time and get in touch with such persons every year. Followup by mail has proved to be quite successful and much less expensive than personal visit. The chief problem at present lies in the failure of ophthalmologists to give quite the complete data that is desired. However, efforts will be continued to solve that problem.

As concerns the Model Reporting Area, Mr. Meyer indicated that New Jersey would have no great problem in supplying the required data.

Miss Elliott indicated that the New Jersey register does not use a card system but rather a ledger system. This was started on July 1, 1961. It has been working with speed and accuracy.

**NORTH CAROLINA:** Miss Anderson stated that it will be necessary to accelerate the reporting of cases receiving services other than Aid to Blind and vocational rehabilitation in view of the fact that information on such other service cases flows from the local level to the State level. In the case of Aid to Blind and vocational rehabilitation the flow is in reverse direction.

An effort will be made to get more complete information on the eye examination report. Miss Anderson believes that this will not be too difficult. In addition, efforts will be made to get more precise and definite information on "age at loss of sight."

There will be a change in procedure of updating on a periodic basis. Instead of clearing the register biennially, it will be done every year. Miss Anderson indicated her belief that conversion to an IBM system from the current manual one should solve some of their problems in this connection.

**RHODE ISLAND:** According to Mrs. Johnson, the Rhode Island register of the blind has been in existence since 1930. Although originally sex, race, and age were not included on the register card, these items were added a few years later and have proven to be quite helpful in furnishing information on request. She indicated that transferring the register card to a punch card would be of great assistance in the preparation of statistical reports. Her statistical unit is very much in favor of such transfer.

Mrs. Johnson brought out the fact that in Rhode Island the Governor's Office desires to know how many of the registered blind were mute, deaf, or retarded. At the present time she is unable to furnish such information.

She planned to do mail updating of her register starting on July 1, 1962.

**VERMONT:** Miss Cole stated that although the register has been in existence almost 90 years, she did not really know what use had been made of it.

All of the eye examination reports received since public assistance started in 1937 have been kept. Recently she reviewed these reports to determine whether in Vermont there had been an increase in blindness from diabetes. As a matter of fact she found that in Vermont they were getting more persons registered with blind-

ness from diabetes than from almost any other cause of blindness.

Although the Vermont Division of Services for the Blind has not required eye reports from all of the new referrals, especially the aged or those requesting talking book machines, it is her intention to get a much higher percent of eye reports than had been the case.

There is a good relationship in Vermont between the Division and physicians. Miss Cole believed that making reporting of blindness mandatory would destroy some of this relationship. When a physician or any agency refers the name of a blind person to the Division, a carbon copy of the letter from the Division to the blind person, describing available services, is sent to the referring source. This, in Miss Cole's opinion, helps to build good relationships.

In Vermont the system of updating is effective because it is combined with part of the public information system of actually sending a newsletter to blind persons. In view of the fact that there are only 719 names on the Vermont register, the cost of mailing such newsletters, even first class, is approximately forty dollars. When such newsletters are sent out, some come back marked "Deceased," "Moved - Left No Address," and so forth. However, Miss Cole remarked that what is not known is how many relatives merely keep the letter and don't do anything about it, even though the addressee has died or left the State.

The Division is looking into the possibility of converting the register to punch cards.

Quite a number of tabulations, such as age distribution, etc., are prepared in connection with new referrals. Most of such referrals are made through the talking book program. There is under consideration an attempt to publicize the availability of services for the blind through radio spot announcements. This may help to get additional new referrals.

#### V. a. STATUS REPORT ON THE NATIONAL SOCIETY FOR PREVENTION OF BLINDNESS CLASSIFICATION OF THE CAUSES OF BLINDNESS

Dr. Ralph G. Hurlin, Chairman, Committee on Operational Research, National Society for the Prevention of Blindness.

The Committee on Statistics of the Blind, jointly sponsored by the American Foundation for the Blind and the National Society for the Prevention of Blindness, developed its recommended standard classification of the causes of blindness in the early 1930's. It underwent some revision in 1940 preparatory to its use in the study by the Federal Bureau of Public Assistance of causes of blindness among recipients of Aid to the Blind. A manual on the use of the classification by Miss C. Edith Kerby was published at that time. Some further revision of the classification was made in 1957 and in 1960, but without revision of the manual, although need for a new manual has been apparent.

The former Committee on Statistics of the Blind became in 1960 a standing committee of the National Society for the Prevention of Blindness, and is now the Committee on Operational Research of the National Society. A subcommittee, consisting of Dr. Maria Fraenkel, who is Director of Medical Statistics and Records of the Department of Hospitals of New York City, and Dr. Hurlin, has been preparing a new manual on use of the classifications during the past several months. The task is not yet done, although the most important part of the manual has been prepared. This part is a new index of diagnostic terms, designed for use in coding the diagnoses found in physicians' reports of the causes of blindness.

The index is intended to be inclusive, or substantially so, of the terms that are used by physicians in diagnosing the causes of blindness. It is much more extensive than the previous index, and consists of a simple alphabetical

list of terms, in place of the former separate lists of affection and etiology terms. In separate columns, opposite each diagnostic term is given the indicated affection or etiology code number, or if as in many cases, one term is indicative of both the ocular affection responsible for impairment of vision and its etiology, both code numbers are given. It is believed that the index in this arrangement will greatly facilitate the coding procedure, and that with this help the task can be managed by a responsible statistical clerk, with referral of relatively few questioned reports to a supervising ophthalmologist.

The new index was referred several weeks ago to the two ophthalmologists who are members of the parent Committee, Dr. Richard E. Hoover of Baltimore and Dr. Ira Jones of New York, for verification. They were asked to delete terms of conditions which are not properly to be considered causes of blindness, to add missing terms, and to verify the assignment of code numbers. This has proved to be a considerable request. Assurance has been received, however, that the lists will be returned very shortly, but without checking of the codes. Other arrangements for verifying the codes will be made and it is expected that the index and other main features of the manual will be submitted to the parent Committee, for adoption or other action, at a meeting to be held on May 19, 1962. If approval is given, the manual can then be completed very shortly.

The manual will, of course, include the proposed Standard Classification itself, discussion of the principles of the classification, definitions of certain terms that affect the comparability of cause-of-blindness data, and a suggested new physician's report form for collection of cause data.

There are being recommended a few changes in the classification itself, most of which are editorial only. The important changes are the subdivision of four of the categories under "General Diseases", in the "Etiology" part of the classification, which appear very desirable in view of the growing importance of the role of general diseases as causes of serious visual impairment. This is largely due to the in-

creasing average age of incidence of such impairment. By combining the few subdivided categories, comparability with the present classification can be preserved.

The suggested report form in its present stage asks for the main ocular affection responsible for loss of vision and *also* for the affection which was its antecedent, if any, rather than asking only for the *primary* affection, as is now the usual practice. Many ocular diseases progress from one part of the eye to another, and one type of ocular affection often leads to another. By placing emphasis on the main affection found by the examiner, it is believed that greater uniformity and usefulness of the reported and classified data should result.

Finally, it should be emphasized that the manual, unless this position is disapproved by the full Committee, will recommend that only cause data that are reported by qualified eye physicians, that is by ophthalmologists, should be accepted for compilation of statistics of causes of blindness. The proposed report form, therefore, ends with a line for the signature of the "examining ophthalmologist" rather than the "examining physician."

This is a point that needs consideration in planning the standards for the Model Reporting Area for Blindness Statistics. One of the present requirements is that cause data will be reported for all registered persons meeting the standard definition of blindness. But the registers now include, and probably should include, persons whose visual impairment is certified by general physicians or by optometrists. Since one important object of the registration project is to ascertain through the registers the true prevalence of blindness as defined, it is clear that all persons meeting the definition should be included in the register. But it is believed that no data on the causes of visual impairment that have been supplied by optometrists, certainly, or by physicians who are not truly skilled in diseases of the eye, should be included in compiling standardized statistics of the causes of blindness. Dr. Hurlin stated his strong belief that the register records should show the discipline of the examiner certifying, or reporting, the degree of visual impairment

of the registered person, and that only those registered persons for whom cause data have been supplied by an ophthalmologist should be considered in compiling statistics on causes of blindness.

#### b. DEVELOPMENT OF STATISTICS ON CAUSES OF BLINDNESS

Mrs. Elizabeth M. Hatfield, Consultant in Statistics, National Society for the Prevention of Blindness.

Mrs. Hatfield indicated that the National Society for the Prevention of Blindness has long been interested in the development of good statistics on causes of blindness. It is only on the basis of data regarding the number of blind persons and, what is even more important, the causes of blindness and their relative frequency that it will be possible to have sound planning and evaluation of prevention programs.

The Society believes that the organization of the Model Reporting Area for Blindness Statistics offers a unique and challenging opportunity to work toward the production of really meaningful and reliable statistics on the causes of blindness. It is only through such organized effort and cooperation that the success of this program can be assured.

For the development of sound statistics on causes of blindness there are certain basic requirements which it would be desirable for the members of the Model Reporting Area to meet. These are as follows:

- (1) Assignment of the responsibility for coding cause of blindness (or supervision of the coding) to a single person on the staff.
- (2) Provide for the services of a consultant ophthalmologist. This ophthalmologist should be familiar with, and understand the underlying principles of the standard classification, and willing and able to provide the necessary consultation time.
- (3) Adoption of a standard report form for the classification of diagnostic data. It is most essential that diagnostic information be reported in the same manner

for all blind persons so that cause statistics will be comparable.

- (4) Development of a good working relationship with all ophthalmologists. It is only through the cooperation of informed and interested ophthalmologists that statistics on causes of blindness can be improved.
- (5) Establishment of a query program for the purpose of improving the reporting of causes of blindness and securing complete and satisfactory diagnoses for classification. It should be the responsibility of the examining physician to designate the cause of blindness. It is only through a query program that he will become aware of classification problems and acceptable reporting.
- (6) Participation in a quality control program. Such a program is essential to insure uniform use of the classification and comparability of statistical summaries from individual reports. This program will involve the submission to a central point of a monthly sample of eye examination reports for review and evaluation of the cause coding.

The development of statistics on causes of blindness is based on the reports of eye examinations made by ophthalmologists. If reports from optometrists are acceptable to the agency and there is no mechanism for securing additional diagnostic reports from ophthalmologists, then these reports must be excluded from cause tabulations.

To provide instructions to cause of blindness coders in the member States of the Model Reporting Area, it is planned to hold a Workshop early this fall. This is essential to insure uniform use of the Standard Classification of the Causes of Blindness. At this Workshop the underlying principles of cause of blindness classification will be discussed and the classification and manual of instructions reviewed. There will also be ample time for practice coding of sample records and a discussion of editing and coding procedures as well as acceptable interpretation and classification. At this time suggested procedures and recommenda-

tions for implementing the program described above for the development of really reliable statistics on cause will also be discussed.

In the meantime it is suggested that the States continue present procedures with respect to cause of blindness coding. It must be kept in mind that, as a result of the Workshop, certain changes in classification and modifications in present thinking and interpretation will be necessary. Whether or not Area statistics on causes of blindness can be produced for 1962 is a matter for discussion at the Workshop. In any event it appears that the development of cause data on newly reported cases of blindness only will be feasible for the immediate future.

#### Discussion:

Dr. Goldstein stated that, in his belief, the National Institute of Neurological Diseases and Blindness would underwrite the support of a workshop or workshops as well as the travel expenses of staff members of the National Society for the Prevention of Blindness designated to assist the States in adopting the Standard Classification of the Causes of Blindness.

Mrs. Johnson indicated that in Rhode Island either an ophthalmologist or optometrist may certify as to blindness. However, the consultant ophthalmologist reviews each report and if any further information is needed, the client may be referred for an ophthalmological examination. She stated that about 15% of the optometric examinations are approved without further referral for an ophthalmological examination. However, in every case, she emphasized that the consulting ophthalmologist certifies to the fact that this person is blind.

Miss Anderson stated that in North Carolina the State supervising ophthalmologist will approve an optometrist's report for Aid to Blind and prevention of blindness for only a three-month period, after which time the person must be re-examined by an ophthalmologist.

Dr. Hurlin agreed that it is desirable that the supervising or consulting ophthalmologist review every report and indicate that he is satisfied that whoever has examined the person

has made the right decision as to blindness. But certifying as to what the cause of blindness is remains an entirely different matter. In Dr. Hurlin's opinion, the latter should be done only by an ophthalmologist. He stated that, in his opinion, the supervising ophthalmologist, no matter how good he was, could not decide what the cause of blindness was merely by looking at the eye report.

Mr. Grabhorn mentioned that in Kansas there is complete agreement with Dr. Hurlin's contention that medical information should be submitted by an ophthalmologist. As a matter of fact, in a new policy to become effective within the next month or two, Kansas will pay for the eye examination for anyone applying for services for the blind. This program would cover not only blind persons but anyone with an eye problem which could be helped with medical care. However, the State will pay only for ophthalmological examinations. It has always paid for optometric examinations in the case of applicants for Aid to Blind. This will still be continued. But where payment is for examination in order to certify eligibility for any other service, it will have to be an ophthalmological examination.

Mrs. Hatfield wondered whether an ophthalmological examination would be required for a person who is on the register but is not receiving any services. Dr. Cummings stated that in Delaware a person would not be considered blind unless an examination report were received. However, if a person goes to an optometrist, that report would have to be accepted also.

Miss Anderson stated that there are clinics all over North Carolina. Men from Duke University are used usually for these rural clinics if there is no ophthalmologist living within the area, that is, accessible to the area and willing to go. In such cases a \$5.00 fee is paid for a visit to the home in which case the nurse accompanies the doctor from the clinic.

Mr. McCollam stated that in Connecticut there are occasionally cases that are bedridden or confined to home with paralysis or multiple sclerosis or something of that sort. Such a person would be reported as being blind by the local physician with the causes indicated in accordance with his best diagnosis. Mr.



McCollam stated that if the course indicated by Dr. Hurlin were followed, then Connecticut could not accept the report of the physician as a basis for blindness or the etiology. It would then mean trying to get an ophthalmologist to go to the home of the patient to make an ophthalmological examination of a person who is seriously incapacitated. Even though the cost for such an examination would be rather excessive, the real problem would be to get an ophthalmologist to travel out to a rural section of the State to make the examination.

Dr. Cummings stated that in Delaware most of the people in nursing homes have had their examination before they went there. However, Miss Cole stated that in Vermont there are more incapacitated blind people getting into nursing homes all the time. If such cases are going to be excluded from the register just because they are not examined by an ophthalmologist, it is going to distort the statistics.

Dr. Hurlin replied that the omission of such cases would not make the statistics distorted, but rather that the statistics are distorted because the cases are included. In other words, he indicated that it was a case of mixing good data with bad data. He would much rather have incompleteness and have good data than to have a mixture and have something for everybody.

Mr. Meyer remarked that there must be kept in mind the fact that an attempt is being made to develop acceptable statistics from a working organization. One must take into account the extent to which it is expected that routines of that working organization be modified in favor of the development of these statistics. He did not see how, if an organization wants to have a proper analysis of its own records, it could exclude certain examinations. In his belief there should be a place on the card where the examination is indicated as unsatisfactory rather than to omit it completely.

Mr. Meyer emphasized the point that the Model Reporting Area program ought to be geared to the situation where no one could accuse the Area of complicating the records because it was trying to get good statistics out of them.

The simpler the records can be made, the better. For that reason he would say that data secured on blind people should be as all-

inclusive as possible and that nobody should be thrown out by virtue of the type of examination that has been received. He did not want any coders to exclude cases of blindness. He stated that he could not see the day coming when people with both eyes extracted are going to be required to go to an ophthalmologist just because statistics are desired.

Dr. Ferree pointed out that the optometrist has usually not had very much training in pathology. This is an increasing problem for the schools of optometry because of the resolution passed by the American Medical Association which makes it difficult for an ophthalmologist to teach in a school of optometry. As a result, it is quite impossible to get appropriate teaching in pathology in the schools of optometry at the present time. The resolution referred to was passed about 1950 by the American Medical Association and since then the pathologists have not been teaching in the schools of optometry. This will not help the undergraduates in optometry, since they are expected to serve blind people.

Dr. Goldstein remarked that perhaps a way out of the dilemma might be to include as an item of information, "discipline of the examiner" so that if it is desired to separate data in order to compare the cause of blindness data submitted by ophthalmologists and non-ophthalmologists this could be done. In other words, take a good look at the information and see what it shows.

Mr. Goldberg stated that one should not confuse the reporting of an individual as blind with the cause of blindness. Individuals should not be excluded solely because they are in a nursing home if they have been classified blind by a competent individual. Whether the Model Reporting Area would accept cause data when there is no ophthalmological examination is another matter. The distinction should be kept in mind. There will be no attempt made to deplete the register. It may result merely in having a group on the register where the cause is unknown. In his opinion, the point raised by Dr. Goldstein would be a very first approach in evaluating this problem and hopefully in the long run to get all ophthalmologists' reports on these individuals.

Miss Ford mentioned the fact that in Louisiana they have codes for type of examiners, and it would be relatively easy to determine the discipline of the person sending in the report and also whether or not the supervising ophthalmologist accepted the report.

Dr. Quade suggested that it be recommended, not required, that everyone have an ophthalmological examination. Also, he suggested that to the items considered essential there be added one additional item, namely "discipline of the examiner."

Mr. Goldberg emphasized that nobody will be excluded from the rolls or register of an agency on the basis of whether or not the person has an ophthalmological examination or an optometric examination. The individual is classified blind if he meets the definition as determined by the appropriate examining discipline, whether it be an optometrist or an ophthalmologist.

Mr. Meyer inquired whether it will be necessary for the coder to know all the ophthalmologists in the State and their precise classifications, that is whether they are diplomates or not. He feared that this might be quite a task for the coder to determine.

Dr. Ferree stated that all ophthalmologists are not board certified. The categories are: ophthalmologists that are board certified; those that are not board certified; the eye-ear-nose-and-throat men because they include more than just ophthalmology in their practice; and the large group of general practitioners. He believed that the eye-ear-nose-and-throat men are largely almost as competent as the uncertified ophthalmologists. It would be fairly easy to get a list of board certified men and those who give ophthalmology or eye-ear-nose-and-throat as their specialty. These lists could be obtained relatively quickly from either a specialist's directory or the American Medical Association Directory.

Dr. Goldstein undertook to summarize some of the thinking that had taken place and the discussion. He indicated that practically every State has a consulting ophthalmologist on staff or on call to certify to blindness, based on either a report of an ophthalmologist or optometrist, or in some cases a general

practitioner, etc. This merely certifies to the fact that the individual concerned had visual acuity of or below a certain degree, nothing else. In other words whatever the indicated cause of blindness or lack of such indication, all those meeting the Model Reporting Area definition remain on the Model Reporting Area register. As long as they meet the State definition, they will still get service. There will be no change from what has taken place. The cause of blindness for the people who do not have an ophthalmological examination would be considered unknown until they do get an ophthalmological examination.

Further discussion indicated that there was a need for having the discipline of the examiner recorded, that is, the person who has seen the patient, not the consulting ophthalmologist who merely passes on a written report. Where an individual gets examined by an optometrist and gets onto the register, he will be reported in the tabulations. If at a later period he is examined by an ophthalmologist, a new card will have to be filled out for such a patient. This is an item that will be updated as time goes on. Tabulations on causes of blindness would exclude data based on optometric examination. If persons examined by an optometrist are later re-examined by an ophthalmologist, then cause of blindness data would appear in such tabulations.

A motion was made to record the discipline of the examiner with the understanding that the details as to the breakdowns into types of examiners would be worked out later as part of the standard information. The motion was seconded and passed without any opposition.

## VI. TECHNICAL DETAILS PERTAINING TO THE PREPARATION OF ANNUAL TABULATIONS

Dr. Dene Quade, Biometrics Branch, National Institute of Neurological Diseases and Blindness

This discussion was based on the publication "Recommended Tabulations, Preliminary Report," which was included among the materials presented to the participants at the meeting. It

was stressed that the report was "preliminary," with changes to be made in it as a result of decisions taken during the Conference.

### 1. Calendar Years versus Fiscal Years

Dr. Quade stated the belief that it would be best for the Model Reporting Area to publish data on the basis of the calendar year. This is generally easier to work with than a fiscal year. Also, since estimates of population are usually available as of July 1, the calendar year would be convenient in finding incidence rates. He noted that during Mr. Goldberg's presentation of the Standards for Membership it was agreed that tabulations would be prepared on a calendar year basis. However, some indication was desired as to whether calendar year tabulations are possible for all States; and if not, whether there is a specified fiscal year which would be more convenient.

Mr. Meyer indicated that it would be more convenient for New Jersey to make tabulations on the basis of a July-to-July fiscal year, although his agency could do it on a calendar year basis. Dr. Cummings indicated that Delaware also uses such a fiscal year, but that tabulations need not be made on that basis. Miss Anderson of North Carolina, Mr. McCollam of Connecticut, and Miss Wickberg of Kansas all expressed a preference for the calendar year. This was because the persons who actually do the tabulating are busy with many other tabulations at the end of the fiscal year. Mr. Meyer felt that it would be more useful for the State agencies to have tabulations on a fiscal year basis in connection with their budget requests to the legislatures. However, Mr. Goldberg indicated that the timing of calendar year tabulations might well be even more convenient for this purpose.

### 2. Details Desirable Even in Excess of Publication Requirements

Dr. Quade pointed out that the Model Reporting Area is calling for fairly detailed tables. It could not possibly publish as much detail as is being requested. There are to be detailed

tabulations from each individual State, some of which would not have enough cases for these cross-classifications to have very much meaning. So in many cases the Model Reporting Area would add together the tables from all its member States in order to produce a combined table for publication. However, it is understood that all tabulations submitted by the member States would become part of a reference library or archives of the Model Reporting Area and that any data which they might contain would be available on an individual basis to any qualified requester who wished to have such data. The National Institute of Neurological Diseases and Blindness would feel free to provide such detailed data from any one State to any other State, or to the National Society for the Prevention of Blindness or the American Foundation for the Blind, for example, even though the data might not appear in the Annual Report. Another reason for having detailed tables is that at some later date it might be decided that emphases will be changed, that something else is needed. If details have been tabulated already, it may be possible to go back to past tabulations and reconstruct tables in accordance with changes in thinking which may occur later.

### 3. The "State Table"

Dr. Quade reviewed some of the proposed tables.

The first one, called the State Table, (see Exhibit 1) would present data from each individual State. All the other tables would be summary tables for the whole Model Reporting Area or for as many States of the Area as could produce the data in that particular table.

The State Table would represent the movement of cases onto the register, the movement within the register from one category to another, and the movement off the register.

Beginning with the first column of the table, there would be requested the total number of cases on the register at the beginning of the calendar year. (The second column, or not transfer, is explained later.) In the third column would be requested the number of new cases first known during the year. In the fourth column would be the number which were re-registered

VI - Exhibit 1 - State Table

(State Name)	On Register 12/31/61	Net Transfer	Accessions During 1962		Removals during 1962					On Register 12/31/62
			First Addit	Re- Addit	Death	Left State	Recov. Vision	Unable to locate	Other	
Total										
Age	0-4									
	5-9									
	10-14									
	15-19									
	20-24									
	25-29									
Sex	30-34									
	35-39									
	40+									
Race	Male									
	Female									
	Unknown									
	White									
Race	Negro									
	Indian									
	Other									
	Unknown									
Specialty	Anomalies									
	Myopia									
	Glaucoma									
	Cataracts									
	Retinopathy									
	RLF									
	Macular Deg.									
	Nerve Atrophy									
	Uveal Tract									
	Other									
	Evid. Insuff.									
	No Report									
Etiology	Inf. Dis.									
	Acc.,Pois.,Vtol.									
	Neoplasms									
	Diabetes									
	Vascular									
	Other Gen. Dis.									
	Prenatal n.e.c.									
	Unk. to Set.									
Vision	Evid. Insuff.									
	No Report									
	Absolute									
	Light Perception									
	Less than 5/200									
	5/200-9/200									
Vision	10/200-19/200									
	20/200									
	Restricted Field									
	Unab. to Det.									
Vision	No Report									

after having previously been on the register, but having been subsequently removed because they had left the State or had recovered their vision or for some other reason. Then would be recorded the number of cases who had been removed during the year, subdividing these according to the reason for removal: death, leaving the State, recovering vision, being completely unable to locate, or other. Finally, there would be the number of cases that remained on the register at the end of the calendar year. All these items would appear on the top line of the table.

The next section of the table would give the same movement items, but classified according to age. In the other sections these movement items would be classified by sex, by race, by major groupings of site and type of affection, by major groupings of etiology, and by degree of vision. However, there would be no cross-classifications in this table.

The second column, or net transfer column, would operate as follows: For example, suppose a boy were four years old at the beginning of the year. Then he would be five years old at the end of the year. Thus he would appear in the second line of the table, age group 0-4 at the beginning of the year; but would appear in the third line, age group 5-9, at the end of the year. He would then contribute a minus one to the second line of the net transfer column, and a plus one to the third line. The figure resulting in a given age group after all such transfers had been made would indicate the net gain or loss resulting from younger persons growing into it and older persons growing out of it. The entire set of positive and negative entries in the net transfer column would indicate whether the register is getting an older or younger population, whether information was being obtained where it was previously missing, and such things.

This table would provide the only data on removals from the register since they would not be tallied anywhere else in this set of tables. Also, this would be the only table giving data from individual States; all the other tables would summarize data from different States.

Miss Cole requested further explanation of the "net transfer." However, Mr. Goldberg and Dr. Quade reassured her that this item need not

be produced by the State agencies; it can be obtained by addition and subtraction as part of the editing procedure in the Biometrics Branch office.

#### 4. Other Tables Requested from Member States

Dr. Quade proposed that each State produce "Detailed Tables," which would include cross-classification of incidence and eventually of prevalence by age, race, and sex against site and type of affection, against etiology, and against degree of vision. (See Exhibit 2.)

With punch cards it would require little time to produce these "Detailed Tables" since there is no real difficulty involved. If the register cards had to be hand-sorted, such sorting would first be by age group. This would give a number of stacks, one for each age group, that would make it possible and relatively easy to complete the age-specific tables, each age group appearing on a separate page. There would be 22 age categories in all, including the category "unknown."

Finally, from each member State there would be requested a cross-tabulation of etiology against site and type of affection, using the Standard Classification of the Causes of Blindness. (See Exhibit 3.)

Mr. Meyer inquired whether individuals who had been examined by an optometrist or other non-medical person would be excluded from tabulations. Dr. Quade indicated that all registered persons would be included, although those without ophthalmological reports might all be listed as unknown with respect to site-type and etiology. Dr. Hurlin requested that discussion of this latter point be deferred to another meeting, and this was agreed to by general consent.

Miss Cole inquired as to the justification for using five-year age groups. Dr. Quade replied that this would allow considerable flexibility. If the Model Reporting Area could get detailed age data it could combine categories in any convenient manner. This would be necessary so that comparisons might be made with data of other agencies. For example, in a recent attempt to obtain age-specific prevalence rates, Dr. Quade found only one suitable break-point, namely under 65 and over 65, which was

VI - Exhibit 2 - Detailed Table

Age Group \_\_\_\_\_

State of \_\_\_\_\_

☐ Register Incidence for the year 19 \_\_\_\_\_

☐ Register Prevalence as of 12/31/ \_\_\_\_\_

Race and Sex	Grand Total	Total		White		Negro		Indian		Other		Unknown	
		M	F	M	F	M	F	M	F	M	F	M	F
Total													
Site/Type													
110													
121													
.													
.													
.													
980													
990													
Etiology													
11.0													
12.0													
.													
.													
.													
98.0													
99.0													
Vision Group													
0													
1													
.													
.													
.													
9													
X													

# VI - Exhibit 3 - Cause Table

State of \_\_\_\_\_

☐ Register Incidence for the year 19 \_\_\_\_\_

☐ Register Prevalence as of 12/31/ \_\_\_\_\_

<div> <div>Etiology</div> <div>Site/Type</div> </div>	11.0	12.0	-	-	-	-	99.0	Total
110								
121								
.								
.								
.								
.								
.								
.								
980								
990								
Total								

provided in nearly all published tables. He mentioned that the Bureau of the Census publishes age data according to five-year age groups, so that corresponding rates could be calculated. Finally, he pointed out (in reply to a question from Mr. Meyer) that tabulation in this detail involves no extra difficulties for States which maintain their registers on punch cards. Mrs. Johnson stated that she needs data referring to children of pre-nursery school age, nursery-school age, and according to various levels of schooling. These groupings would not correspond to the proposed five-year groups. Mr. Goldberg explained that in such a case it would be necessary to put breakpoints in the age distribution both where she wanted them and also where the Model Reporting Area wanted them, so that addition of data from two or more subcategories would be required to obtain some of the desired groups. He pointed out that it would be very difficult, if not totally infeasible, to attempt to provide an age classification which would satisfy the needs of every single State. However, Dr. Hurlin and Mrs. Hatfield indicated that there was no need for five-year groups over the entire range of ages. They felt that eight to twelve categories would be sufficient. Dr. Hurlin suggested that there might be three or four groups below ten years of age, then perhaps twenty-year groups up to sixty, and five-year groups thereafter; Mrs. Hatfield suggested that groups might be set up corresponding to infants, pre-school children, school-age children, young adults, adults 40 through 64 years of age, and then those 65 and over. Dr. Hurlin suggested that a final decision in this matter could be delayed for some time. He said that the first problem is to obtain some good cause data. If one or two States would make some analysis of their data this would permit drawing some conclusions as to what form the tabulations should take. Mrs. Hatfield thought that cause data, at least at the start, should be restricted to the new cases only. Dr. Quade pointed out that States would not be required even to have coded causes for all their old cases before three years had passed. It appeared to be the general consensus that further discussion of this point should wait for a subsequent meeting.

Dr. Hurlin expressed an objection to the term "register incidence." He felt that the Model Reporting Area should get away from using the term "incidence" for all cases that are discovered for the first time, whether new blindness or old blindness, because it would invite the people who use the data to make misjudgments; the number of accessions to the register is not the same as the incidence of blindness. He stated (in response to a question by Mr. Meyer) that "incidence" of blindness represents new cases of blindness within a specified period. This is what is most wanted, an indication as to how much blindness occurs within specified periods, and as to whether it is increasing or decreasing. He agreed to a suggestion by Mr. Meyer that such indications might be found by coordinating data on newly-reported cases with data on their age at onset of blindness. Dr. Goldstein declared that the term "incidence" certainly would be changed, perhaps to "accessions." Dr. Hurlin stated, however, that he did not object to the term "register prevalence."

#### 5. Tables to be Published

Dr. Quade reviewed for the Conference the tables which would actually appear in the Annual Report of the Model Reporting Area, as distinct from those which would be requested from the member States.

First, it is planned that the State Table would be published for each individual State.

Second, there would be a tabulation by race and sex against age, against major groups of site and type of affection, against major etiology groups, and against degree of vision (see Exhibit 4). The tables for the Model Reporting Area would be obtained by taking the various Detailed Tables submitted by member States and adding them together.

Third, there would be a table of site and type of affection by age, (see Exhibit 5), which would again be obtained by adding together data from the various member States. In this table would be given the detailed codes for site and type of affection from the Standard Classification, and these would be cross-tabulated against age, with age categories somewhat broader than five-year groups. There would also be published another table exactly



VI - Exhibit 4 - Characteristics of the Blind

Race and Sex		Grand Total	Total		White		Negro		Indian		Other		Unknown	
			M	F	M	F	M	F	M	F	M	F	M	F
Total														
Age	0-4													
	5-9													
	10-14													
	15-19													
	20-24													
Education	Less than High School													
	High School Graduate													
	Some College													
	College Graduate													
	Postgraduate													
Cause of Blindness	Refraction													
	Cataracts													
	Glaucoma													
	Retinopathy													
	Other													
Other Medical Conditions	Diabetes													
	Hypertension													
	Stroke													
	Heart Disease													
	Other													
Visual Function	Light Perception													
	Counting Fingers													
	Reading Large Print													
	Recognizing Faces													
	Other													

VI - Exhibit 5 - Site and Type of Affection by Age

Site and Type of Affection	Age					
	Total	0-4	5-14	- - -	85+	Unknown
Total						
Eyeball in General						
110 Glaucoma						
121 Myopia, detachment of retina specified						
"						
"						
190 General affection of eyeball, not specified						
Conjunctiva						
"						
"						
"						
"						
"						
"						

like this one, except that it would have etiology instead of site and type of affection.

Finally, the detailed cross-tabulations of etiology against site and type of affection to be requested from the member States would be added together to produce a Cause Table for publication.

The State Table would include data on both new and old cases. Each of the other tables

would appear in duplicate, one for new cases (additions and re-additions) only and one for the entire register. However, the tabulations of the entire register would not be required until three years after admission of the State to the Model Reporting Area.

Mr. Meyer inquired as to the attitude of the National Institute of Neurological Diseases and Blindness with respect to the accumulation of

cated that a State is perfectly free to include any other items of information that it needs for its own use, and that this would even be encouraged, since local needs come first. Dr. Quade pointed out that all the required tabulations are based strictly on items which are required by the Standards to appear on the register card. None of the required tabulations refers to items classified as only "desirable" rather than "required." Mr. Goldberg observed that the tables which had been presented are basic types of tables. It might be convenient to publish data on additional items from two or three States which are able to produce such data, even though these items were not required and not all States would collect them. Supplementary tabulations of this sort might be very helpful in showing the direction one should go in adopting new standards for the future.

Dr. Graham indicated dissatisfaction with the title "Characteristics of the Blind" used for the table in Exhibit 4. He stated that the term "the blind" is imprecise and misleading and carries an unsatisfactory philosophical connotation; it should be "the legally blind," "the visually impaired," "the totally blind," or some such thing. Dr. Cummings and Miss Cole suggested that the term "the blind" might be replaced by "blind persons," which would soften it a bit although not actually add any precision.

Dr. Graham also desired to go on record as encouraging people to collect more statistics than the Model Reporting Area is requiring. In particular the American Foundation for the Blind has great use for data on social characteristics. The Foundation would be glad to help in the interpretation of such data.

## VII. TECHNICAL DETAILS PERTAINING TO THE MAINTENANCE OF REGISTERS

Dr. Dona Quade, Biometrics Branch,  
National Institute of Neurological  
Diseases and Blindness

This discussion was based on the publication "The Use of Punch Cards for Registers of the Blind, Preliminary Report," which was included

from it. It was stressed that the report was "preliminary," with changes to be made in it as a result of decisions taken during the Conference.

### 1. Sample Register Card

Dr. Quade presented a sample register card (see Exhibit 1) and indicated that it would not be possible to recommend a *standard* card useful for all registers of the blind, because the needs and interests of the various agencies would differ. The *sample* card includes only those items which are required or which, although not required, are strongly recommended by the Biometrics Branch. This card is 5" x 8" in size. Its reverse side, left blank, might be used for keeping a record of contacts or of services rendered, or for adding more changes of address than are provided for on the front, or just simply for general comments.

The card provides for the following items:

- a. Name
- b. Register Number

It was recommended that a system of register numbers be used, providing for quick and easy identification, which might help prevent duplications in the register. It might make it easier to provide data to outside agencies because it would be possible to preserve confidentiality if registrants were identified by number instead of by name. It was suggested that register numbers be assigned in serial order — the first blind person on the register #1, the next #2, and so forth. There should be no attempt to have the register number include any other information; in other words, no attempt to assign certain kinds of numbers to males and other kinds to females, or a certain kind of number to persons living in one county and another kind to persons living in another county. This usually leads to confusion or difficulty.

Furthermore, when a person is removed from the register, his number should not

## VII - EXHIBIT 1 - SAMPLE REGISTER CARD

## REGISTER OF THE BLIND - SUMMARY CARD

Name					Register Number	
Sex		Race		Date of Birth	Marital Status	
Month	Year	ADDRESS		Town	County	Inst. (Code) (Code)
Month	Year	EYE EXAMINATION by: (Code)		Cause (NSPB) Site/Type Etiology	Vision	(Code)
Age at Loss of Sight		Source of Report			Date Added to Register	

(Form Number)      Date removed from register \_\_\_\_\_ Reason \_\_\_\_\_

be assigned to anyone else. There have been problems in working with the records of one State which reassigned old numbers, so that the same number might apply to more than one person. By the same token, if the person removed from the register is restored to it, he should receive his old number again.

- c. Sex
- d. Race
- e. Date of Birth

It was suggested that the date of birth, including month, day, and year, be recorded, although the requirements of the

Model Reporting Area would be satisfied with month and year alone.

f. Marital Status

g. Address (including county)

An agency would want to have space provided for an address. The sample card provides space for three changes of address, so that when the address changes the next line of the card is filled out without erasing the old address. The back of the card might be used for addresses beyond four or else a new card might be started. Each change of address should be listed with the date, so that there would be some indication of

how long the case has been living in his present and other locations. Space has been provided for recording the county name and also for a county code with the idea that a punch card could be prepared, perhaps directly from the register card.

**h. Institution**

It was recommended that there be kept a record of residence in the major institutions in which the blind people live in the State. There are two reasons for this. First, there might be interest in the institutionalized blind, ~~perso~~. Second, when the annual clearance of the register is conducted, instead of writing individually to persons who are institutionalized, all those who reside within a single institution could be grouped and inquired about at one time.

**i. Eye Examination**

The first eye examination received would be recorded on the first line, showing the date of the examination (month and year), the name of the examiner, and his discipline which could be coded. Space on the card is left for more than one eye examination, so that if the person has had, say, three examinations, they appear one after the other. Thus, the whole history of a person's eye examinations appears on this single card.

Whenever an eye examination is received, the register should be checked. If it is a new examination on a person already registered, the results of the new examination should be recorded on a new line of the card. Furthermore, the punch card should be corrected in accordance with any indicated changes. Space has been provided for recording the month and year of the eye examination so that it would be possible to know, with respect to data on the causes of blindness or on the degree of vision remaining, exactly how recent these data are. If an eye examination were ten years old, for instance, then one might suspect that the

status of the registrant might have changed, particularly with respect to degree of vision.

**j. Cause of Blindness**

The sample card provides for the coded cause of blindness, including site and type of affection as well as etiology. This would make it necessary to have the code handy, perhaps on the wall next to the register for ready reference, or else to squeeze the written description on the card.

**k. Vision**

Space has been provided on the card for recording the specified degree of vision remaining, together with the code for it for each eye.

**l. Age at Loss of Sight**

**m. Source of Report (or Source of Referral)**

**n. Date Added to Register**

**o. Date Removed from Register**

**p. Reason for Removal**

**Discussion:**

Mr. Meyer inquired as to what should be done about register numbers when, as in New Jersey, records come from the counties, which have their own numbering system. Dr. Quade recommended that a State-wide numbering system be adopted, even to the extent of having two numbers for each case, if the county numbers are also necessary. Mr. Meyer indicated that his Commission has been registering by name; they have had no difficulty so far, although they have considered numbering. It would probably be possible to adopt a special "C-number" for the Commission. Mr. Goldberg observed that a similar situation obtains in Louisiana. Confusion may result when an individual moves from one parish to another because then his number must be changed in the State records. An individual should have a register number

which would remain the same no matter where he moves within the State.

Miss Cole asked for a statement as to which of the items on the sample card are required. Dr. Quade replied that most of the items are required. Name and register number are not, so to speak, required, but one could not get along without name. Sex, race, and date of birth are required, but marital status is not a required item. With respect to the address, the county is the only required item; institutional status is not required. Under eye examination, the date of the examination and the name of the examiner are not required, but the discipline of the examiner would be required according to the decision reached earlier in the Conference. The cause of blindness and the vision group in coded form are required, but they are not required to be written out in full. Age at loss of sight is a required item; the source of report or source of referral is not a required item. Finally, the date added to the register, the date removed from the register, and the reason for removal, are all required.

Mr. Meyer inquired as to the value of recording marital status. He stated that items which are likely to change a great deal should be kept as few as possible. Dr. Quade replied that the American Foundation for the Blind had indicated a particular interest in this item. Mr. Bridges wanted to know whether marital status would refer to the time of addition to the register, or whether it would have to be updated all the time. Dr. Quade indicated that updating would be necessary, although usually marital status does not change too often. Dr. Hurlin suggested that marital status might be replaced by birthplace, since there is a good deal of interest in where cases originate. Dr. Quade mentioned that to his knowledge birthplace is now recorded on only one register. Dr. Graham pointed out that one of the reasons why marital status is of interest is that quite often, particularly for older people, it gives some idea of the degree of isolation to which they have been subjected, although this is admittedly a very rough index. He indicated that this is a useful item; it is a lot of trouble but it is worth that much trouble. Mrs. Hatfield added that one would need to know whether the person was living with someone

else, and not just the marital status. Miss Anderson mentioned that her agency records living arrangements, which would include that information. Mr. Cooper remarked that it is not possible to anticipate the need for all the items that might eventually be wanted. With regard to items of which the status changes, he suggested that one might consider sampling the records at some time in the future, rather than trying to maintain a changing status for all.

Dr. Cummings observed that age at loss of sight as a requirement will be very difficult to get. Dr. Quade indicated that there are no plans at present for tabulating this item. Attempts should be made to obtain it, and it should be recorded where available, but it would be understood that there would be quite a number of "unknowns" for that item. Mr. Goldberg added that an approximate date would be sufficient for this. Mrs. Hatfield commented that one bit of information which will be obtained here is whether the person has been blind since birth. This is generally reported and it is very helpful to know. When they become blind later in life, the age might not always be reported, but at least some useful information would be obtained.

## 2. Vision Groups

Dr. Quade reviewed the vision group code. Although this particular code had been approved by the Planning Group it was still subject to discussion before being adopted permanently. The code is as follows:

- 0 Absolute blindness
- 1 Light perception (and/or projection) only
- 2 Motion or form perception, but less than 5/200
- 3 5/200 through 9/200
- 4 10/200 through 19/200
- 5 20/200
- 6 Better than 20/200, but field restricted to 20° or less

- 9 Unable to determine exactly (but presumed within the Model Reporting Area definition)
- X No report as to the exact degree of vision (but presumed within the Model Reporting Area definition)
- R Not within the Model Reporting Area definition of blindness (for registers which use a wider definition)

#### Discussion:

Mrs. Hatfield suggested that it should be specified how such notations as "hand motions" or "counts fingers" should be coded. Dr. Quade agreed with this, adding that there should not be any special categories for these, but that the categories in which they fall should be defined. Mr. Goldberg suggested that this should probably be recorded in the revised standards.

Mr. Meyer questioned the usefulness of classifying the degree of vision into so many different categories. He admitted that at a full staff meeting of his agency he had found considerable sentiment for recording detail on the basis of its general value; however, he, himself, did not see any need for more than two categories, with the breakpoint at 5/200. From the standpoint of reference to individuals, he did not feel it would be of value to the case worker, who is supposed to look at the complete case record and is sufficiently well trained to distinguish between widely differing degrees of vision. Furthermore, he did not think it of value from the standpoint of mass data, because the vision of two persons technically in the same vision group may actually be very different in terms of usefulness. Therefore, knowledge of the number of persons in a particular vision group might not be of any great interest. However, Mr. Meyer agreed to go along with the decision of the Conference.

Dr. Graham admitted that what is really wanted is a measure of visual efficiency. The interest is not in a person's measured visual acuity, but rather in the degree to which he uses what vision he does have. However, at present this is far too sophisticated a concept

for national statistical purposes. On the other hand, statistics on visual acuity are useful because ophthalmologists have a tendency to certify people for Aid to the Blind or other programs at 20/200 without specifying what residual vision there might be below this limit. From detailed breakdowns would come all sorts of insights which might not be useful in individual cases but might give guidelines for national programs, such as mobility training.

In this connection Dr. Graham observed that there is a great deal of difference between light perception and light projection. If the individual had light perception he would know whether or not light was present but he could not discern the source of the light; this latter ability is light projection. In the rehabilitation program absolute blindness and light perception are lumped together in one code category of "no useful sight;" then light projection, which is useful for personal orientation, is in a separate category. Mrs. Hatfield remarked that the distinction between light perception and light projection is very rarely made on eye reports. The report forms would have to be changed in order to get this additional information. She was not sure whether it would be worthwhile to do that.

Mrs. Hatfield stated that it would, in fact, be very useful to know how many persons are totally blind, and how many have specified amounts of vision remaining, rather than just knowing that all are legally blind, because this latter category covers such a wide range. She felt that it would be worthwhile to consider the associations between degree of visual impairment on the one hand and age, cause of blindness, or abilities of the individual, on the other. Although there has not yet been available sufficient data at this point for analysis, she suspected that there might be a lot of implications worth looking into.

Dr. Goldstein remarked that the Committee on Definition of Blindness, which holds periodic workshops under the sponsorship of the National Institute of Neurological Diseases and Blindness, is trying to devise a form which would stimulate ophthalmologists to make better reports of visual acuity below 20/200, as well as of near vision. It used to be that doctors

reported nearly all human gestation periods as 40 weeks, but when a careful study was made it was discovered that there is considerable variation with all the nearby weeks on either side of the 40 weeks being equally well represented. In the same way, reports of visual acuity of 20/200 are undoubtedly not correct in the great majority of cases. If better data could be tied together on a national basis with the need for rehabilitation, or the results of rehabilitation, something very worthwhile might result.

Mr. Bridges wondered whether detailed information on degree of vision remaining is not intended primarily for the purposes of evaluation and study at the National Institutes of Health. He indicated that his own agency would use instead the person's capacity or ability to use his vision, which would be available from the case folders. However, although he did not know exactly what would be done with information on degree of vision, it would be used for studies.

Mr. Goldberg remarked that in dealing with mass data one has a different problem from that involved in dealing with individual data. Even if it were not possible to get functional vision as such, a much better estimate of it could be secured from the suggested vision groups than from simply knowing that all registrants met the Model Reporting Area definition. Conclusions from such estimates would at least give guidelines, even if they were not always valid for individual cases. Unfortunately, such data are not available anywhere at present. Hence, it would be very desirable to collect them.

Dr. Goldstein indicated that once the data are available, there are all sorts of useful possibilities for study. For example, one could compare one's own State with other States, which might help to interpret rehabilitation results. Mrs. Hatfield remarked that if the vision groups were entered into punch cards one could, for example, make a special study of persons with visual acuity less than 5/200 or of those with visual acuity between 5/200 and 10/200. One could just pull the specified group of punch cards, identify the corresponding cases, and go to the original records for further study. Mr. Goldberg added that it would be

particularly convenient for certain types of research if one could take only the group of interest rather than the entire register.

Miss Cole inquired about keeping information on degree of vision up-to-date. She noted that the vision remaining tends to decrease, and that with every new eye report the records would have to be changed. Dr. Quade remarked that there is no plan to conduct a program of examinations of registrants just to find out whether or not their degree of vision had changed, but that the degree of vision appearing on the card would simply be that found in the last examination of record. However, if another examination is obtained for some other purpose, then the card should definitely be corrected in accordance with the changes indicated.

### 3. Annual Clearance

Dr. Quade reviewed the question of how to go about making a clearance of the register, that is, performing the annual updating.

One of the requirements of the Model Reporting Area is that a contact should be made with each person on the register at least once a year. Obviously, the best way to do this, *from the standpoint of statistics*, would be to make a visit to every registrant every year, and in fact, at least two States are doing exactly that. However, for most States this would not be feasible, and they would undoubtedly want to conduct some sort of preliminary weeding out of registrants whose status could be verified without a visit.

First of all, there would be no need to make a special visit or send a special letter to persons receiving services. One might go down the list and mark off those registrants who are receiving Aid to the Blind or vocational rehabilitation, or who have a talking book. Persons receiving services may be considered verified. This would take care of something on the order of one-half to three-quarters of the register.

Next, one might make lists of the registrants who reside in specific institutions. Then, instead of contacting the individuals, one could write to the institution, including such lists, and state that: "These persons are registered



with the agency as being legally blind." "Are they still living in the institution?" "Does the institution have any reason to suppose that they are not blind any more?" "Does the institution have any additional names to be added to the list?" This is one of the reasons why it was suggested that institutions be included on the register cards. If they were coded on the punch cards, then the needed lists could also be made very easily.

After this, one would probably want to do as most of the States with large registers do, namely send out a letter to the remaining persons on the register. These letters would go with a request for Form 3547 from the Post Office. On this form the Post Office would report if the person has moved and left a forwarding address, or if he has died, and so on. There would be no advance payment for this - only if the Post Office actually had to send something back. If this form were not requested, and the letter were forwarded but no response were obtained, then in following up on it one would go back to the old address without knowing about the new one.

The letter might be sent in a window envelope so that the name and address need be written down only once. It might say that the agency is maintaining a register and has the recipient's name on it. It might offer services, since those who receive such letters are presumably not getting any services. With the letter might be included a brochure describing the work of the agency. The letter would request a reply, and for this there would be enclosed a card on which postage would be paid. On the card would be written the registrant's name and address - that is what appears through the window in the envelope - and the registrant would be requested to correct it if there were any error in it. There might also be some checkboxes for him; for example, one saying "Please send me further information about your services" and another saying "Please do not contact me this year." Some people might feel that it is not a good idea to be continually sending out such letters to registrants. However, it is believed by the Biometrics Branch to be a very good idea and a very convenient method for getting the register updated.

Some of those receiving the letter will respond, and they would be considered verified. On the other hand, some will not, and it would be necessary to follow them up - by phoning them or visiting them personally, or by finding someone who can definitely verify that they are still living where it was thought they were and that they are still blind. However, the number of persons remaining to be included in this followup procedure should be very small.

#### Discussion:

Mr. Bridgee observed that it would be a great convenience if the register were maintained on magnetic tape with a computer. Then the addresses could be obtained on a simple request from the tabulating room. Magnetic tape is available in Louisiana and might be used for the register. Dr. Quade agreed that a great saving in clerical time could be made if magnetic tape were available. The reason for not putting addresses on punch cards is that a punch card has only 80 columns. Thus, if the addresses were included then there would not be much room left for anything else. With magnetic tape there is no limitation in the amount of information that can be recorded on each registrant. Furthermore, it would probably be possible to arrange things so that the addressing of envelopes would be done automatically. However, all this is pretty much irrelevant because very few agencies have access to magnetic tape.

Mr. Meyer brought up the point which he had raised on the previous day. In view of the fact that considerable volume of materials would have to be mailed, and that this would be for the purpose of complying with the requirements of a program sponsored by the Public Health Service, he said it should be possible to use the franking privilege. Dr. Hurlin said that he understood that the Bureau of Labor Statistics extends the franking privilege to all the State agencies which collect employment and unemployment statistics. Dr. Goldstein stated that he would look into this matter but he indicated that it would take some time to get a decision on the matter.

Mr. McCollam stated that his agency was just beginning a mail check; he inquired as to what proportion of answers to his letters might be expected on the basis of experience in other States. Mr. Sullivan indicated that in Massachusetts the letters are sent out in the Spring. About 65% of these letters are answered by May. Then stragglers come in over a period of up to six months, so that eventually between 75% and 80% of the letters are answered.

#### VIII. OTHER BUSINESS

Dr. Goldstein informed the Conference that, at his suggestion, the administrators represented at the Conference had met and elected one among them to represent the States on the Planning Group for the Model Reporting Area for Blindness Statistics. The person they had elected was Mr. George F. Meyer, Executive Director of the New Jersey Commission for the Blind. Mr. Meyer would serve in this capacity for one year, after which an election would again take place.

Mr. Remein, a member of the Planning Group and also the Grants Research Officer, Division of Chronic Diseases, informed the Conference of opportunities in his Division for research support for studies using register populations. The research program for support of applied research in the areas of vision is located in the Neurological and Sensory Diseases Service Branch. This Branch is developing a project

grant mechanism to support studies of different types.

Dr. Goldstein told the Conference that the Second Annual Conference of the Model Reporting Area for Blindness Statistics would be held in Bethesda, Maryland, in about a year. He mentioned that in future years, however, it might be more desirable to vary location of the meeting annually from State to State. This would make it possible for member State agencies to become familiar with the operations of the blindness agencies in other States. The National Institute of Neurological Diseases and Blindness would underwrite the cost of these meetings. Member States will be canvassed for agenda suggestions sufficiently in advance of the meeting.

Materials produced by the Biometrics Branch will be circulated to the member States to keep them abreast of developments. Furthermore, the Branch would like to act as a clearinghouse for the Model Reporting Area. If the member States produce any materials that they wish to have circulated, such materials should be produced in sufficient quantities and sent to the Biometrics Branch for circulation.

The Biometrics Branch would be pleased to assist the States in any problems in which it could help. Inquiries in this connection were invited.

Dr. Goldstein requested the Conference participants upon their return home and after a chance to think over the meeting, to send to the Biometrics Branch any comments about the Conference, including suggestions for improving future ones.

The Conference adjourned on March 27, 1962, at 12:28 p.m.

## APPENDIX A

### History of Blindness Statistics in the United States

Ralph G. Hurlin, Ph.D.<sup>1</sup>

The history of blindness statistics in the United States is a long one. It goes back 180 years. It's notable not for the success of the efforts that have been made during that time, but largely for what these numerous efforts have shown about the deficiencies of our procedures as well as the results.

I can't begin to do justice to this subject in the time that is available, but I would like to remark that it's well worth going back over the history to see what efforts have been made, what experiments have been tried, and learn from the experiences of the past.

Before speaking about some of these efforts, I would like to comment that we need statistics of blindness in four categories, three of which Dr. Masland has already mentioned, but I didn't catch the fourth one, which I think is of fundamental importance. We need prevalence data to get at the magnitude of the problem. We need to know how many people are blind. We need incidence data even more than we need prevalence data. If we had incidence data, we would soon have prevalence data. We need cause data if we expect to control the problem and prevent the part of blindness that is preventable.

In addition to that, there is one other category to which much too little attention has been paid thus far, and that is, we need statistics of the degree of impairment.

All through this history, 180 years, we have been making attempts to collect statistics of blindness, to produce data on blindness, while giving scant attention to the question of the degree of impairment. The result is that we

haven't known when we are through what we have been dealing with. To be sure, we have had over some of this period definitions of what we aim to record, but we haven't gone back and tabulated our data by degree of impairment. I submit now that in order to know what we are dealing with in any survey, in any census, any collection of data, we need to know degree of impairment in order to make comparisons between results.

Let me say a word about the census data first. The Federal Census began collecting data on blindness in the fifth decennial census, the census of 1880, and each successive census through 1930. For 11 censuses, the Bureau of the Census attempted to compile useful statistics of blindness.

For the first two censuses a line was put on the bottom of the enumerator's schedule on which the enumerators were simply told to list the people enumerated, who were blind. That was all the instruction given.

The enumerators were responsible for deciding who was blind and the degree of impairment that justified notation.

In the next five censuses, a column was inserted on which the enumerator was to check if the person was blind.

About 1870, I believe the enumerators were asked to fill out a card with the name and address of the person whose name was checked as blind, and then for several censuses thereafter, names and addresses were taken on slips and special schedules were sent back. In 1880, not only were schedules sent back and follow-up

<sup>1</sup>Chairman, Committee on Operational Research, National Society for the Prevention of Blindness.

communications resorted to, but correspondence was had with institutions dealing with the blind by which additional names were obtained.

In 1880 the Bureau of the Census, on the basis of evaluation of the results of the census of the blind obtained in 1820, was substantially convinced that this effort was not worthwhile. Although agencies for the blind petitioned and urged, that the census of the blind be repeated in connection with the population census, they were discontinued after the 1880 census. After 1880 the Census Bureau has not attempted to collect statistics of blindness in connection with the general population census.

The report of the 1880 effort states that with the procedures that can be used in the general population census, it is not worthwhile to attempt to collect these data; only unreliable information can be obtained in this form.

It is interesting that although I haven't taken time to speak about the changes in definition, except to state that at first the enumerators were responsible for deciding who should be called blind, about 1860 or 1870 the first instruction to the enumerators was given, and the first intimation of what was intended to be meant by blindness.

In successive censuses the instructions and definitions were changed, presumably with improvement. As you go back over this record you see that in all probability in the first decennial censuses (probably the first five or six) the enumerator was to count only people who were totally blind. In evaluating those data one reaches the conclusion that certainly not all of the totally blind persons in the population were enumerated.

In 1880 a new procedure was adopted of paying enumerators five cents a name for filling out a schedule with the name and address of the person found to be blind. Whether it was the added compensation or not, the census of 1880 gives the highest rate of enumerated blind persons to population. That rate was just about one blind person per thousand.

But again when one evaluated those data, you find that in all probability there were a great many persons missed by the enumerators. In fact, the follow-up attempt to get additional names through agencies and institutions yielded,

I believe, about 20 per cent more than the enumerators themselves had found. It is true that there was some duplication between the names from the two sources.

The Bureau of the Census stopped its attempt to do anything in the way of producing statistics on blindness with the census of 1880, when they merely enumerated blind persons, and made no follow-up study. The data of that census were processed and a report issued. It was a relatively brief one, whereas the 1920 census report on the blind and deaf mutes — the data largely concerning the blind — was a publication of 200 pages.

Every conceivable analysis of those data was made, and yet the only conclusion that can be reached concerning them is that they are not reliable. The author of that report put tremendous effort into the work in order to make all possible use of the data. But it seems to me he drew some hazardous conclusions, including one that the rate of blindness had declined because the enumerated blind persons per thousand, or hundred thousand population, from 1880 through 1920 showed a marked decline.

It is dangerous to use data that are not adequately protected in the process of collection and analysis for conclusions.

During the decade of the 1920's and on into 1930, a great deal of interest in statistics of blindness developed in the State agencies. Numerous State agencies made surveys in an attempt to start or to improve their registers. In a great many of these cases statistical material was produced as a result of the survey. Some of those data were decidedly useful.

I have found the North Carolina figures of extreme interest. It seems to me that North Carolina tells us more about prevalence than we know from other sources, except perhaps the National Health Survey, about which I want to speak.

The National Health Survey was conducted, I believe, in the winter of '34-'35. The main data, collected from over 700,000 families, was obtained in urban areas, some 83 cities. There were a few, 23 I believe, rural counties also studied. But no attempt was made to balance rural and urban population, so that most of the data are for the urban population.

That was a monumental study. Tremendous pains were taken in making it. The enumerators were paid through the WPA or CWA program. They were trained for ten days which is obviously much better than the training given the census enumerators. Great care was taken to impress on these enumerators the task of enumerating persons with diseases and disabilities.

That Health Survey, however, was concerned with all diseases and disabilities, and not simply blindness, and probably the data on blindness suffered to some extent on that account.

The enumerators in that survey were told to ask who in the family was blind, and to record the name of that person. If the respondent mentioned that somebody was partially blind, or had partial sight, that person was also enumerated. But the attempt was to get the totally blind person, and yet no definition of blindness was clearly stated. These were people who had substantially no sight left, and a sentence in the instructions reads, "The partially blind will not be recorded." In other words, the aim of the study was not to enumerate the partially blind.

The data were checked. Medical data on all the persons enumerated in the study were collected after the enumeration and were carefully used. I have not found in the report of the study any detail as to how the ophthalmological information turned out. However, it is stated that, for all diseases, the National Health Survey found that the information obtained from clinics and hospitals and doctors subsequent to the enumeration tallied very well, even on causes, with what it learned from the respondents. I am not talking primarily of blindness because the report isn't specific there. Yet it's difficult for me to understand how respondents can give us the cause data that we need. In other words, for cause data we need medical information and, in my opinion, data returned by specialists and ophthalmologists.

I just want to point out the work that the Aid for the Blind program has done in keeping track of statistics of recipients of assistance. The study it made in the early '40's I believe was a good pathfinding attempt.

I also want to point to the work that Miss Kerby and Miss McKay of the Foundation for the Blind jointly did in repeated studies of causes of blindness in pupils of the schools and special classes for the blind. That work was started as early as 1934. Those studies were continued, Mrs. Hatfield is now working on one, the results of which may be published very soon.

In closing may I say that Miss Kerby and Miss McKay were the prime movers in organizing an informal conference which preceded the census of 1930, in which various people sat down with representatives of the Bureau of the Census to talk about the desirability of collecting data on the blind in that census.

In getting ready for this meeting I looked over my notes of that meeting. One of the things that struck me in looking over these notes was that in the course of that discussion it was pointed out then that if we could have good registers of the blind, State by State, we could hope to get much better statistics of blindness than we could get through enumeration of the blind in any population census.

Dr. Goldstein is now showing us the way after 30 years to realize that expectation.

#### Discussion:

Mr. Meyer raised the question as to whether the census of 1880 also turned up a large number of cases that were not blind. In reply, Dr. Hurlin indicated that almost all the blind persons enumerated received letters from the Bureau of the Census requesting further information relative to their condition. From the replies it appeared that an appreciable proportion of those enumerated as blind were blind in one eye and some were not blind at all. Thus, it would seem that the enumerators not only failed to enumerate all people who were blind, but they enumerated some people who were not blind. Many of the latter were eliminated before the report was prepared.

## APPENDIX B

### Declaration of Purpose of Model Reporting Area for Blindness Statistics

Hymen Goldstein, Ph.D.<sup>1</sup>

This is an auspicious occasion for all of us and for the blind. It marks the first time in the history of blindness statistics that a group of States, the national voluntary blindness agencies, and the Federal Government have undertaken a concerted effort to improve data collection and statistics on the blind.

The Model Reporting Area for Blindness Statistics was conceived out of frustration, a frustration that arose when numerous attempts to secure statistical information on the blind and their characteristics on a national basis for legislative and other purposes, met a blank wall. Even estimates, subject to large and undetermined errors were, in some cases, impossible to make.

The dedication by which the Model Reporting Area can grow is one devoted to helping States achieve more uniform statistics, and thus allow them to satisfy to a greater degree many administrative, service and research functions of a State agency for the blind.

Encouraged by Dr. Hurlin's work, and recognizing the continued need for uniform and reliable statistics on the incidence, prevalence, and causes of blindness, the Biometrics Branch, NINDB, explored the possibility of utilizing an existing instrument, the blindness register, to satisfy this need. It was clear that even the existence of reporting laws and mandatory registers in many States did not, in itself, insure uniform and reliable statistics. It was also clear that a uniform definition of blindness was essential to uniform statistics. However, the existence of the laws and registers did

suggest a means by which such statistics could be achieved.

If the register totals could only reflect, to a greater degree, all cases of legal blindness defined by a common definition, and if the register could only give the essential data for each such person, there would be a basis for building up a meaningful body of statistics on the blind. There would finally be an answer to the persistent and unanswered question, "Who are the blind?"

The Biometrics Branch conceived the idea that States maintaining blindness registers would be willing to agree to collect specified essential data on each blind person and make concerted efforts to keep their registers up-to-date. A Planning Group for the Model Reporting Area - consisting of members of the National Society for the Prevention of Blindness, American Foundation for the Blind, Division of Chronic Diseases of the Public Health Service and the Biometrics Branch of the National Institute of Neurological Diseases and Blindness - was called together a year ago and the idea of a Model Reporting Area presented to them. Approval was unanimous.

Thirty-nine States throughout the country were thought to have registers of the blind. The staff of the Biometrics Branch took on the task of visiting each of these States, and 85 of them were found, in fact, to have registers. Interest in the idea of a Model Reporting Area was extremely high in the State agencies, although a number of them admittedly had registers that needed considerable work to make

<sup>1</sup>Chief, Biometrics Branch, National Institute of Neurological Diseases and Blindness.

to show enthusiasm for the concept of a Model Reporting Area. Much information was gathered in each State concerning the type of data collected, the use to which the registers were put, procedures used in keeping the register up-to-date, etc. These findings were brought back to the Planning Group which approved the objectives of the Area, and certain standards for membership. In accordance with the approved standards, and based on information obtained by staff visit to each State agency concerned, as well as on information secured by questionnaire from these agencies, an evaluation of each State's capacity and willingness to satisfy the Model Reporting Area's standards was made by the Biometrics Branch. These evaluations, submitted to the Planning Group, constituted the basis for acceptance into the Model Reporting Area.

The Biometrics Branch also undertook to act in a coordinating and technical capacity for the Area, and agreed to furnish consultation and other assistance, where necessary, to the States accepted into the Area. Working jointly with the Biometrics Branch in providing Public Health Service assistance to the States is the Neurological and Sensory Disease Service Branch of the Division of Chronic Diseases.

The 11 States accepted into the Model Reporting Area comprise about 15% of the total United States population, including 15% of the total white population and 17% of the total nonwhite population. A comparison of Model Reporting States with non-Model Reporting States indicates that white-non-white and male-female breakdowns are almost identical percentage-wise in the two groups of States.

The number of persons on a register at a given time constitutes register prevalence. Using the best information available, the average register prevalence rate of blindness in these 11 States is 1.7 per 1000 population. This rate seems to be similar to that for 19 other States with register prevalence data. However, it should be pointed out that, unless one knows how complete reporting is and the extent to which the register itself reflects the actual number of living blind in the State, it is not

it is expected that possibly an additional 5 or 6 States will become eligible for the Model Reporting Area within this coming year, since requests for assistance have to date been received from a number of States.

Each Model Reporting Area State has subscribed to the following objectives of the Area:

1. To improve the statistics available on the reported blind so that it will be possible for member States to arrive at comparable register incidence (that is, the number of new cases reported to the register during a given period of time) and eventually, register prevalence. By requiring the uniform reporting of certain demographic data, it will be possible for these States to determine the reported incidence and prevalence by age, sex and (in most cases) race. This incidence and prevalence may be subdivided into the various types of blindness by site and etiology.
2. To allow the Federal Government and the national voluntary agencies in the field of blindness to arrive at pooled reported incidence data and, possibly prevalence. Again, these data may be made specific for various demographic and medical factors. On the basis of reported data from the States in the Area, along with other supporting information, it may be possible to estimate similar data for States not in the Area. As the Area grows, the errors of such estimates should diminish.
3. To encourage and assist in conducting studies of etiology, survivorship, and characteristics of the reported blind population.

Where a State maintaining a blindness register cannot meet the standards for admission to the Model Reporting Area, the Biometrics Branch's consultative services are available, upon request, to assist it in meeting the standards. When a State, interested in membership, believes that it has met the requirements, it will be

considered for membership. Furthermore, the Biometrics Branch's services are available to any State that does not now have a state-wide register to assist it in setting up a register to be maintained by a single State agency.

The services of the Biometrics Branch include assistance to States, particularly those with large registers, in putting the register on a punch card system so as to enable it to satisfy the needs of the Model Reporting Area, (such as in the preparation of tabulations), and, at the same time, to provide a means of more effective utilization of the register for local needs.

A register places in one State agency a central source of statistical information on incidence, prevalence, causes of blindness, visual acuity, and demographic and other characteristics of the registered blind population. In the absence of a standard definition of blindness and uniformly collected data, statistics derived from registers of many States may result in confusion, even though they presumably relate to similar populations. A Model Reporting Area register is one where the emphasis is placed on getting such information as uniformly and reliably as possible, within the limits of the type of information being collected. It is one that will permit the comparison and pooling of inter-state data, making available, for the first time, statistics on a multi-State basis for all the registered blind meeting a common definition as of a given time period. We are looking to the day when these Area data will represent the whole nation. Statistics secured through the Model Reporting Area will be available to States, national, voluntary and other interested agencies, thus reducing, to some degree, requests from various agencies to individual States for identical statistical data.

Attempts are being made and will continue to be made to publicize the Model Reporting Area for Blindness Statistics and the purpose for which it exists. A brochure is being prepared which will give in some detail the development, purpose, and program of the Model Reporting Area. This will include a statement of objectives, history of the Area, membership requirements, procedures for application, and whatever definitions and tabulations have been

agreed to by Area members. A paper dealing with the Model Reporting Area will be presented at the next Annual meeting of the National Society for the Prevention of Blindness to be held in Indianapolis, April 11 through 13 of this year. It is expected that this paper will be published in *The Sight-Saving Review*. Furthermore, the attention of the National Council of State Agencies for the Blind is being directed to the development of this Area in the hope that States that are now without registers of the blind will be interested in the services of the Biometrics Branch in assisting them in setting up such registers. It should be mentioned that the concept of a Model Reporting Area is not a new one at the National Institutes of Health. In 1951 the Model Reporting Area for Mental Hospital Statistics was initiated and has now been in existence for 11 years. That Area includes 27 States and accounts for some three-quarters of the total U. S. population.

The member States have a great stake in the Model Reporting Area for Blindness Statistics. Their ideas and suggestions will be sought in the further development of this undertaking. The availability of a highly competent Planning Group, consisting of Mrs. Elizabeth M. Hatfield, Dr. Ralph G. Hurlin, Dr. Milton D. Graham, Dr. Eric Josephson, Mr. Richard E. Onken, and Mr. Quentin R. Remain, to assist in setting policy, is and will continue to be of great importance. The active support of the two national voluntary agencies for the blind is one that should help to underwrite to a large degree the success of such an undertaking. The Biometrics Branch of the National Institute of Neurological Diseases and Blindness and the Neurological and Sensory Diseases Service Branch of the Division of Chronic Diseases will furnish whatever assistance the Public Health Service can make available to States in improving their statistical endeavors. It is expected that annual meetings will be called of the Model Reporting Area at which time developments that have taken place during the year, as well as plans for the future, will be thoroughly discussed. Reports of these meetings will be made available to participants.

It is hoped that the existence of the Model Reporting Area will enlist the cooperation and



support of the Professional community of ophthalmologists and optometrists in bringing about better and more complete reporting of information on the blind. It is obvious that with such support the Area can best achieve its objectives.

The Model Reporting Area by its nature is a team approach. As a lone effort of any one agency, it cannot succeed. As a concerted

effort by the States, the national voluntary agencies, and the Federal Government, it cannot fail. The progress made in one short year in converting an idea into a reality is heartening. It could not have been possible without the encouragement and assistance of the Public Health Service, the national voluntary agencies, a far-seeing Planning Group and last, but certainly not least, the enthusiasm of the States themselves.

## APPENDIX C

### The Register and Blindness Statistics in Canada

Arthur N. McGill<sup>1</sup>

We in Canada, as you have already heard, have developed a register which goes back to the early days of the Canadian National Institute for the Blind (CNIB). We cannot trace our history as far back as you in the United States, but we do trace the beginning of CNIB to 1906.

In 1906 there was started in the general area of Toronto, what was known as the Canadian Free Library for the Blind. Its sole purpose was to distribute library books to adult blind people who had graduated from existing schools for the blind and had no other source of reading material.

This was a very small effort, which continued until 1916. At this time some of the blinded soldiers returned from overseas, and amongst them was our own Colonel Baker. They brought with them a different approach and different ideas about the capabilities of the blind. They thought in terms of an over-all service program and they stimulated the Canadian Free Library to the point where eventually in 1918, the Canadian National Institute for the Blind was inaugurated and received a Federal charter. The charter was granted on the basis of (1) a private organization - which meant it could receive certain grants from the various levels of Government, with its main support coming from the general public, and (2) the charter granted permission to carry on a full and complete rehabilitation program across Canada.

One of the first things that the CNIB did after receiving its charter was to develop a register in order to determine the extent of its problem. As there were no records available, the first step was to write to the schools for

the blind and secure from them a list of their graduates. These graduates were eventually contacted and registered. It also advertised in the newspapers for people who were blind and, through these sources, it gradually developed the beginning of a list of individuals who were known to be blind.

Some of you may recall that in the very early twenties our Canadian Broadcasting Corporation was inaugurated. In order to support this, paid radio licenses were mandatory. The CNIB, through negotiation with the Government, enabled blind people to receive free radio licenses. Each person, however, had to be certified as blind by our organization.

In the course of carrying out this particular program a very large number of blind people made themselves known to CNIB and, from the beginning, we were able to certify many of them on the basis of an ophthalmological report.

I might say that possibly our first registrants with CNIB were in 1918 when the Government requested the organization to carry on the rehabilitation and training for the blinded veterans of the First World War. The Government had registered them under the definition at that time of 3/60, and we also adopted the same definition of blindnes. In each case an ophthalmological report was used.

We carried on from our radio license period, registering people as they came to us, in each case requiring an ophthalmological report. In the rural areas it was often necessary for interviewers or case workers to use a small screening card in lieu of an examination, but which provided information for registration.

<sup>1</sup>Superintendent, Ontario Division, Canadian National Institute for the Blind.

During all this period we, the CNIB, were negotiating with the Government for a Blind Persons' Pension which eventually came through in 1987 as an amendment to the Old Age Pension and, working with the Government, we agreed to supply certification for all blind people over the age of 40 who wished to apply.

In order to do this it was necessary to organize clinics across Canada staffed by ophthalmologists, which provided up-to-date ophthalmological reports, and those who qualified under the definition were of course certified as blind.

I should mention that just prior to this period our definition of blindness changed to 6/60, as did that of the Government, so that in 1987 we were functioning on the 6/60 definition.

Blind persons are referred to CNIB through medical doctors, neurological specialists, ophthalmologists, public health nurses and other agencies doing social service work, as well as the individual himself or his relatives and friends. Since 1945 all persons requesting service from CNIB must be examined by an ophthalmologist in order to be registered.

The information we have gathered over the years has done many things for us. It has permitted us to have an age classification, a breakdown of blindness according to ages which has helped us plan our over-all service program. It has provided statistics for us on which to base our approach to the Federal Government, the Community Chest and the United Appeals, both sources from which we receive necessary funds. Generally speaking, the amount of funds we receive is based on the statistical information we provide.

Our relationships with the Federal Government have been most agreeable. All persons applying for blind pensions, or blindness allowance as it is now called, are referred automatically to CNIB. We cross check our records to see whether or not the person is registered with us, or whether it is to be considered a new case. If the case is new, then we have access to the Government ophthalmological report.

Our register permits us to conduct a Causes of Blindness survey, which we are currently doing, bringing our old information up to date. This is being conducted by one of our own

consulting oculists, two of whom are on the staff, a policy which has been in force for a number of years. The purpose of the ophthalmologists on staff is to check the eye reports, procure more detailed information when necessary from the local oculist and, of course, to carry on our Causes of Blindness survey.

We are in a position through the use of this data to supply the medical profession with basic information on which they from time to time have based research projects.

During the last three years CNIB has been using a punch card IBM system on its register and statistical information. At the present time we are in the process of becoming familiar with the statistics provided and determining how valuable they are going to be to us. We are also learning how much more flexible the system will be and the different types of information it can provide for us.

In Canada there is no compulsory registration of blind people. However, if a blind person wishes to receive an allowance, he of course has to be registered with the Government and fill in the necessary forms. If, on the other hand, he wishes to receive service from the CNIB, he has of necessity to be registered with us and have an ophthalmological report filled in.

We estimate that at the present time our register covers approximately 95 per cent of the blind people in Canada.

To us the completion of our register has been an evolving program, but a very satisfactory and very gratifying one. Without the register it would have been impossible for CNIB to function as it has had to, being a National organization, and the only one of its kind in the country.

#### Discussion:

In response to a question from Mr. Grabhor Mr. Magill stated that the persons on the Canada register of the blind (approximately 95% of the blind people in Canada), all were receiving some kind of service. Miss Hickling pointed out that there are approximately 35,000 blind persons in Canada out of a total population of just over 10 million. This means an approximate

rate of 1.6 per thousand population. The referral from the Canadian Federal Government to the CNIB is automatically for service and is used as such. The register is used for statistical and service purposes. The Blindness Control Division of the Canadian Department of National Health and Welfare sends to the CNIB reports of the ophthalmological examination of any person applying for a blind person's allowance, whether or not he comes within the definition of blindness. Since a number of these do not meet the definition, the CNIB thus learns of many people whose condition does not quite meet the definition. The Blindness Control Division also reports to the CNIB all people applying for blindness allowance but who do not qualify

under the many tests. This enables the CNIB to learn of many additional persons with a definite visual problem. Mr. Magill indicated that in addition to the lack of compulsion in Canada to register a blind person, there was also no compulsion for an ophthalmologist or any other eye examiner to report to the CNIB. No studies have been made to determine how many people are blind but who have not been reported because they are not interested in securing any services.

Dr. Goldstein indicated that the concept of a Model Reporting Area is devoted to getting complete information on all blind persons meeting a common definition, whether such persons are getting services or not. How information on all such persons will be secured will, of course, vary from State to State.

## APPENDIX D

### Blindness Statistics and the National Society for the Prevention of Blindness

John W. Ferree, M. D.<sup>1</sup>

It is really a very happy privilege to participate in this first meeting of representatives from the Model Reporting States, which have come into the movement so far.

I think it is one of the most significant developments we have had in regard to getting precise information of the type that will permit us all to do a much better job than has been possible before. This has been indicated by the previous speakers.

My purpose this morning will be simply to indicate to you what we at the Society, with our particular interest in prevention, conservation and restoration of vision, see in the programs that you will be initiating and getting ahead with in the coming months and years.

As you know, the Society has for a number of years, and I think Dr. Hurlin indicated this very well, back in the very beginning really of the Society's existence, had an interest in the collection of better data referring to the problems of blindness.

In 1908, the beginnings of this Society took place around the problem of ophthalmia neonatorum. The data accumulated by a special commission in New York State, jointly with the American Medical Association, made it clear how poorly knowledge at that time was being applied to prevent ophthalmia neonatorum. This led to the creation of the Society, to do something about getting better application of that knowledge, which had been available for about forty years.

Our need for statistics, I think, I may say is as follows: First to better define our problem, we need to know how many are blind,

how many go blind each year, and then we need a good bit more information on the specifics, such as age groups, causes of blindness, and how these causes differ by ages. I think it behooves us, too, to give some attention to what the cost of care is for the blind, as a lever to get more funds for prevention.

So that with the kind of information we can get through this statistical approach I think we will be better able to define our problems. This will permit a rifle type of approach rather than the shotgun approach that we all too frequently have to use, because we do not have more precise information. We can learn of those population groups we have from which we can get the most dividends from our prevention, conservation and restoration programs.

Now I shall not give you all I have here as data, but what this has meant by way of pointing up needs, such as the percentage of blind due to ophthalmia neonatorum. I will mention this as an example. In 1907, 28 per cent of blindness in children entering schools for the blind was due to ophthalmia neonatorum. In 1954 the corresponding figure was only one-tenth of a per cent. In 1940, four and three-tenths per cent blindness in the total population was due to ophthalmia neonatorum and in 1957 only five-tenths of a per cent, which gives you some idea as to our interest in showing what can be done with applying knowledge that we may have.

I think you are familiar, as another example, with what happened with retrolental fibroplasia.

This serves to illustrate the use of statistics

<sup>1</sup>Executive Director, National Society for the Prevention of Blindness.

as a tool, in epidemiological research in learning more about the cause of a blinding eye condition, and it helps too in the study of the natural history of the disease.

Statistics showed an increase, and gave us the basis for cooperative research with the Children's Bureau and others in getting research done that discovered the cause of retrolental fibroplasia. And then having discovered the cause, getting the knowledge applied and seeing what a dramatic improvement took place from the 484 cases reported from just seven states, in the peak year of 1952, until now it is an extremely rare occurrence.

I might mention this has significance, I find, for more than just those of us concerned with the blind and the prevention of blindness. I get calls fairly often from lawyers representing one or the other parties in a dispute, or in a suit, as to who was responsible for a child's blindness and as to when this knowledge became available, so that the medical group could be considered negligent if they had not administered oxygen appropriately to a premature infant. If we did not have these statistics to show what happened and when it happened, it would have a considerable implication for those who have been blinded with retrolental fibroplasia, and the medical profession that has taken care of them.

We have as another example our glaucoma screening programs. Because of the statistics we have been able to acquire through these programs, we have learned a great deal more about that problem.

I may say we need to know a good bit more precisely, by way of prospective studies as well as retrospective studies, about the natural history of glaucoma. We do know that we are consistently getting about two percent return on our screening programs, and that the screening programs would indicate that there are about 1,815,000 people over the age of 40 in the country who have glaucoma, half of them not knowing it.

Now in our preschool screening programs, we are finding that of about 32,000 screened this last year, 3,000 were referred for professional eye examinations. This is 1960-1961 school year. These screening programs, with

the statistical information gained from them give us good support for our attempts to prevent blindness due to amblyopia. It also helps to identify those children who have visual problems and can benefit from the programs for education of partially seeing which we are very much interested in along with the Departments of Education.

Another reason for getting statistics has to do with program evaluation and I have indicated earlier that the statistics on trends, for example, measuring what we have accomplished educationally and through service programs all are grist to our mill. We know that there has been a marked shift away from the infectious diseases as a cause of blindness to an increase in causes associated with the aging of our population, such as glaucoma, diabetic retinopathy, vascular diseases and cataracts. These are much more important than previously and it is through statistical information that we learn this.

It also has significance I think for public education programs, so that, as I pointed out earlier, we can pinpoint those population groups that most need attention and promote with them better public use of our available knowledge and facilities and services.

Statistical information gains support for research efforts as well as for our service programs.

I think that unless, as Dr. Masland pointed out, you can present to those responsible for your support, either through tax funds or voluntary funds, what the extent of the problem is and its nature, you are very much handicapped in getting the resources needed to do a job that you know could be done.

This information also has a good bit of importance as far as the direction of research is concerned. Learning where the significant problems exist enables one to stimulate more effectively research in those areas where the need is greatest as we observed, for example in the increase in blindness due to diabetic retinopathy. We are quite aware that here is a problem that has had relatively little research and it would be most important that we stimulate more research in the area of diabetic retinopathy. This would also have further significance as

we would learn more about those blinding eye conditions due to vascular disease.

Now in the past we have met one of our needs for statistical information through studies on the causes of blindness in children of school age. We have conducted these periodically since 1930. We hope to have a report finished soon covering the school year 1958-59.

We have been for a long time, through Dr. Hurlin and his Committee's endeavors, interested in first the development of a classification of the causes of blindness and then in its refinement and revision periodically. As you know, a year or so ago, a revised classification came out. We are presently working on the manual, which we hope to have ready soon, which will make the classification a good usable one. You may be interested to know since World Health Day this year is devoted to the prevention of blindness, that efforts are being made to adopt a classification, with a manual that will be usable throughout the world, so that we can begin to get data comparable from one country to another. I hope very much this will be consummated at a meeting of the International Association for the Prevention of Blindness in December, in New Delhi, India.

I may say it is a bit difficult sometimes to work these things out so that it is agreeable to so many different backgrounds as we have represented in the International Association, but we are hopeful that this will come to pass.

We have in the past worked on special studies with various States in the studies of

the blind and development of cause of blindness statistics. We have done this on the basis of Dr. Hurlin's work in North Carolina which has been a good laboratory State. We have been able to make estimates of prevalence of blindness and causes from its data since about 1940.

Special studies have enabled us to get some information about age group and cause. Other studies have had to do with blindness in pre-school groups and the handicapping conditions of the partially seeing as we observed it in our programs for their education.

I would think the future prospects are extremely bright, if you all are given the resources in your States to go ahead with what is planned here in this Model Reporting Area. We hope it will catch hold and be extended to a significant number of States, significant enough to give us the assurance that our sample is proper and that we can extrapolate pretty generally throughout the country.

I can assure you that the cooperation of the National Society on this will be available in every way possible and that we will be looking to you all for assistance, State by State, in giving us the kind of information you will get through this means, to do a better job of program planning in reference to prevention, restoration and conservation of vision.

We look forward very much to what we anticipate will be the kind of report we will get a year from now at the next meeting of the group.

## APPENDIX E

### The Importance of Uniform Reporting by Agencies for the Blind as Seen by the American Foundation for the Blind

M. Robert Bornett<sup>1</sup>

#### I. General Attitude

1. The American Foundation for the Blind certainly endorses the principle of uniform reporting about blindness in the United States. Data of many kinds are essential to not only a knowledge of incidence and prevalence, but also for purposes of socially useful research and effective service planning.

2. The Foundation endorses the concept that all sources of information about individuals with eye problems should be and probably are willing to use uniform nomenclature and provide basically important data in a consistent manner. Their willingness to do so will depend greatly upon their understanding of the "feedback" of information useful to all who participate.

3. The Foundation does not believe that the achievement of comprehensive reporting, whether uniform or not, is so greatly aided by legislative compulsion that undesirable effects are over-balanced. Laws compelling registration of blind persons *per se*, tend to constitute an invasion of personal privacy and perpetuate the public notion of the "difference" of such people in the group sense. Any requirement to be registered, therefore, should be avoided.

4. Observation of State agency experience with register activity leads the Foundation to believe that virtually all such efforts have met essentially with failure. This probably is due to:

- a) lack of real conviction about the purpose of a State register as useful for planning;

- b) a feeling that funds devoted to register activity are disproportionately high in the light of prevailing inadequate budgets for service;
- c) lack of trained personnel, even where conviction and funds have been available;
- d) the complexity of interpreting the need for cooperation by all pertinent sources of information about individuals with eye diseases and the maintenance of an efficient plan for such cooperation.

5. Currently, and during recent years, the Foundation's consultants to local operating agencies have advised against the effort to initiate or continue a register system. The Foundation would be indeed happy to alter its point of view if the experiment of the Model Reporting Area, under the leadership of the National Institute of Neurological Diseases and Blindness, should evolve plans for efficient, economical, and useful data gathering systems on a uniform basis.

6. It should be noted that both in these discussions and in any situation where an agency's record keeping is under consideration, that the meaning of the term "register" should not be confused with the very important operational requirement of an agency to maintain a client case record system of high caliber. Further, it should be noted that agencies who maintain good client case records are an invaluable source of many kinds of data. It would be highly desirable if such agencies would agree to uniform maintenance of case records for purposes of uniform reporting and/or for efficient use by researchers.

<sup>1</sup>Executive Director, American Foundation for the Blind.



## II. Background and History of AFB Experience and Concern

1. Early awareness of the absence of sound statistical information of any sort;

2. Initiation cooperatively with other organizations of efforts to secure statistical data, both through census and through population sampling;

3. Awareness of confusion about philosophical points of view about the effectiveness of "list keeping" versus the expenditure of public funds and the psychological impact upon individuals and upon social attitudes;

4. Recent project to expose, on an objective basis, the factors which would assist any operational agency to understand purpose, method, and cost of a useful register.

## III. Additional Data Considered Essential by AFB

1. The five basic areas of data contemplated in the Model Reporting Area experiment are solidly endorsed as minimum.

2. The Foundation strongly urges that data about visual acuity should include near vision as well as distance vision. Near vision information is essential to almost all service research and planning, especially in the fields of reading, mobility, education, and employment.

3. In general, the Foundation endorses the listing of additional types of data reported in the minutes of the National Institute of Neurological Diseases and Blindness meeting of December 1961, but agrees that at this time it would be inadvisable to attempt to secure reporting of such an extensive variety of information. It is hoped that a future outgrowth of a successful uniform reporting system would include certain general facts about educational and vocational status.

## IV. Role of AFB in Model Reporting Area Project

1. Will make available to project staff and cooperating groups results of studies of registers now under way;

2. Will coordinate, in so far as feasible, community surveys now being planned by both our Division of Community Services and our Division of Research and Statistics;

3. Will inform our field representatives and program specialists of the nature and details of this program so that they may render supportive consultation in their own field visits; and

4. In general, and upon specific identification of need or occasion, will lend whatever knowledge possessed by own staff for analysis, interpretation, or improvement as progress is noted.

## Discussion:

Dr. Goldstein pointed out that a State did not need to have mandatory reporting in order to be eligible for membership in the Model Reporting Area. Registration of a blind person does not signify that he is different, odd or queer anymore than registration of a patient with tuberculosis, cancer or syphilis signifies that. These are public health problems and registration of cases in some areas of public health may be the only way in which adequate information may be secured for purposes of prevention, control, and service. In registration there is no intent to invade privacy. As a matter of fact, the Model Reporting Area is interested in summary statistical tabulation where no individual is identified. In case it becomes necessary or desirable for the Biometrics Branch, National Institute of Neurological Diseases and Blindness, to work with the punch cards of a given State agency, just enough identification is needed on the punch card to make it possible to check back with the agency when questions may arise about individual data.

Dr. Goldstein indicated that in blindness, as in many other public health domains, a register, to be most effective, should render service. There is no conflict between the concept of getting adequate statistics with that of rendering service. In many States contacting cases on the register periodically in order to update the register and thus improve prevalence statistics is tied in with the death

to render more service, that is, making known to registrants the types of services that are available.

In similar fashion, the State agencies for the blind contact ophthalmological and optometric societies to tell them what is available in the nature of services for the blind. This has the dual purposes of improving statistics on new cases first added to a register during a given period of time, and of making known what services are available to the registered blind.

There is no reliable information available on the cost of maintaining registers. However, it should be obvious from the fact that the cost of maintaining a register must be very minimal if it is maintained by anyone who happens to have the time available. Too often the maintenance of a register is a very haphazard thing. Whoever is available takes care of it. A register is an important established instrument. If it weren't, it would never have been set up in so many States. It is obvious that more time, more personnel and more money should be put into register maintenance to get better and more reliable information.

Miss Anderson indicated that the cost of maintaining a register is minimal compared to the advantages of having good scientific data. The North Carolina program would have been impossible without a register.

Mr. Meyer stated that in New Jersey the law states that the register must be maintained. The register is more or less a concomitant of good filing practices and purposes. One cannot maintain a proper line of service for clients without a highly organized file department that sees that the information is in that ought to be in, that it is made available to workers within the agency, and that it is kept up-to-date.

Mr. Barnett mentioned that one should not confuse a register with a client case record. Keeping uniform client case records is invaluable in itself.

Dr. Goldstein indicated that uniform reliable information on the register card can only come from better records in the case folder.

Dr. Ferree observed the importance of impressing upon those responsible for the original data what these data are being used for. The data coming out of the register is no

better than what goes into it from the person responsible, that is, the ophthalmologist. To really make the Area concept work, the medical profession must be sufficiently well impressed with the fact that the data they submit are going to be useful in answering the problems presented by the blinding eye diseases. From Dr. Ferree's experience as a State health officer with tuberculosis, communicable disease, and cancer registers, he knew of the problems of incomplete reporting. However, in his opinion, every State in the Model Reporting Area has a real responsibility and obligation to attempt to solve such problems in conjunction with the medical profession. Once the physician is made aware of the purpose for which the data are to be used, there is little problem of medical ethics and confidentiality in reporting a blind person to the register for statistical purposes. Whether or not the physician will refer the patient for services depends on how well the services are regarded by the profession, on what the members of the profession think can be done in the interests of the patient, and on how well the physician will carry this conviction to the patient and secure permission to refer him for service purposes. Where the patient does not want the services that are available, a problem may present itself. However, there should be no problem where services are not involved. There are many examples, such as in the registration of persons with venereal disease, as to how to protect the confidentiality of information. It depends largely on how well the profession is educated as to what the State agency has to offer. Members of the profession can pretty well handle the situation with any client if they are sold on it themselves.

Miss Anderson stated that in North Carolina the ophthalmologists and medical examiners are very supportive of the program. She knows of no instance where the client refused to be registered. The talking book service has been an effective way to get clients reported.

Mrs. Johnson emphasized that in Rhode Island it was necessary to meet with each ophthalmologist and tell him that the agency did not intend to force services on any client. All it would do would be to make information known about services available to the blind.

Even if in certain cases no services were wanted, it would still be possible and desirable for the ophthalmologist to register such clients with the agency. Confidentiality would be preserved. The Bureau for the Blind does not wish to take any responsibility for the client away from the physician, merely to share it with him. She pointed out that of 10 persons last year who did not wish services, 4 are now coming in for service.

Dr. Ferree mentioned that physicians are more sophisticated today than they were 10 or 15 years ago in such matters. They realize more acutely the value of bringing resources to their patients and, hence, are not so nearly afraid of doing so.

Dr. Goldstein pointed out that in some measure the solution would be not only in education of the medical profession but also in feeding back to it periodically the results of its labors so that its members could get an idea of the magnitude of the problem, the composition of the blind population, etc. These must surely be of interest to physicians.

Mr. Mungovan stated that in Massachusetts the ophthalmologist is asked to record on the

bottom of the reporting form whether the client wishes any services from the Division of the Blind. Where the answer is "No," there is no attempt made to contact such client in this connection. The records are stamped "Do Not Contact." No further contact is made until the individual comes to the Division with a request for service.

Mr. Meyer indicated that services to the blind are quite costly. There is, therefore, a responsibility upon the agency to have a complete report of the blind person. Such reports, if complete and sound, give a basis of justification for the need for providing services.

Dr. Goldstein mentioned that, with respect to the inclusion of "near vision" in essential information to be reported on each new registrant as suggested by Mr. Barnett, such data if reported reliably and completely would be helpful to the States, the voluntary agencies, and the Federal Government. He stated that the States in the Model Reporting Area will be canvassed to see whether it will be possible to get the ophthalmologists and optometrists to report this item reliably and completely.

## APPENDIX F

### The North Carolina Project

Dana Queda, Ph.D.<sup>1</sup>

It was in the spring of 1961 that the Biometrics Branch, National Institute of Neurological Diseases, proposed the establishment of a Model Reporting Area for Blindness Statistics, and called together a Planning Group which heartily endorsed this idea. The Biometrics Branch then undertook to send staff members to visit every State agency which maintains a register of the blind. One of the first of these visits was made by Dr. Goldstein in April, 1961, to North Carolina.

The North Carolina State Commission for the Blind was designated in 1935 to establish a complete register of blind persons in the State, to keep it currently "validated" (that is, updated), and to compile from it appropriate information about the blind. The State's definition of blindness is somewhat more liberal than the standard definition adopted by our Model Reporting Area: North Carolina recognizes as blind all persons with central visual acuity of 20/200 or less in the better eye with best correction, and those with visual field limited to 30 degrees in the widest diameter (instead of 90 degrees), and also persons with certain other ocular conditions which are considered equally disabling.

A person is actually added to the register when a verification of diagnosis of his blindness is received and approved by the Commission's supervising ophthalmologist. This verification is required before any services can be provided. Furthermore, a statute enacted in 1945 requires physicians, ophthalmologists, and optometrists to report to the Commission,

within 30 days following the examination, all persons whom they find to be blind. Excellent cooperation has been obtained from professional personnel and voluntary agencies throughout the State, so that the register is relatively complete. At present it includes the names of about 13,000 blind persons.

The register cards are made up in duplicate; one copy is kept at the Commission's headquarters in Raleigh, and the other is kept by the appropriate district office, of which there are six in the State. They include the following information taken from the eye reports: name, address (including county), sex, race, date of birth, date of examination, diagnosis, and visual acuity; the date of addition to the register is also indicated on the card. Space is provided on the card for a number of other items, but these are actually recorded only occasionally. The register card does not provide for keeping a record of services rendered. Also it should be noted that the diagnosis, or cause of blindness, is recorded in words only. There is no coding of the causes of blindness, or, for that matter, of any other item.

The register is being updated continuously. As soon as information is received indicating that a blind person has died, left the State, or recovered his sight, his card is removed from the register. If he is known to have changed address, or if his eyes are re-examined, his card is revised accordingly. Well over half of the registrants are receiving services of one sort or another, so it is fairly easy to keep track of them. Changes in status among regis-

<sup>1</sup>Analytical Statistician, Biometrics Branch, National Institute of Neurological Diseases and Blindness.

trants who receive no services may, of course, be missed. However, in the spring of even-numbered years a "master clearance" of the register is conducted. At this time a letter is sent to every registrant who is not receiving Aid to the Blind. The letter invites its recipient to inquire about services. A card is enclosed with the letter, and he is requested to return it, giving his correct address. Those who do not respond are very carefully traced and, if they cannot be located, they are removed from the register.

A tabulation of register data is made every two years, following the master clearance, for the Biennial Report of the Commission. This tabulation gives for each of the 100 counties in the State the number of persons on the register by sex, by race, by present age, by age at onset of blindness, by degree of blindness, and by source of support. There are no cross-tabulations whatsoever. Furthermore, the tabulation gives prevalence data only; no records of incidence are kept. The work is done in the six district offices, each one tabulating its own cards, and the results are simply compiled in Raleigh. Everything is done entirely by hand, with no mechanical aids used. Even so, only two or three other States publish data of comparable detail. In fact, North Carolina has been a pioneer in the field of statistics on the blind. It was this register which Dr. Hurlin used for his work in the 1950's on the prevalence of blindness, which has remained the basis for statistics published by the National Society even today.

Let us consider the North Carolina register in the light of the standards for admission to the Model Reporting Area for Blindness Statistics. Skipping over a few minor points, we see three major difficulties.

First, the policy of the Commission has been to clear its register only once every two years rather than once every year as is required by the Model Reporting Area. However, the Commission has agreed to institute an annual clearance for the future.

Second, the Commission has not been using the Standard Classification of the Causes of Blindness. However, it has indicated that it

is willing to begin coding its cases, after the National Society for the Prevention of Blindness has provided assistance in training staff to do so.

The third difficulty is the major one. Without help, the North Carolina State Commission for the Blind is clearly unable to provide detailed annual tabulations of its register. The North Carolina register is a gold mine of information, but hand-tabulation is the only available method for extracting data. The Commission could not possibly afford to expend even more clerical time and effort for the task of annually thumbing through 18,000 register cards. The obvious solution is to transfer the entire register to punch cards. Yet this would involve an initial expense beyond the means of the Commission.

From the beginning the Biometrics Branch has stood ready to provide statistical consultation to State agencies which maintain registers of the blind, in order to help them improve their registers and meet the standards for admission to the Model Reporting Area. It was our hope that financial assistance could also be provided, although we were not certain whether this would be possible. In August 1961 Dr. Goldstein and I revisited the Commission in order to study its register in greater detail. At this time we suggested the use of punch cards. In November 1961 we submitted a formal set of "Recommendations for the North Carolina Register of the Blind." These included preliminary suggestions for a punch card system. In December I visited the Commission again in order to discuss our recommendations and in order to consider possible arrangements for transferring the register to punch cards. Meanwhile, we had been exploring the possibilities of obtaining financial assistance. We proposed that a contract be negotiated between the National Institute of Neurological Diseases and Blindness and the North Carolina State Commission for the Blind under which the Public Health Service would provide funds to enable the Commission to establish a punch card system. This proposal has now been approved and the contract has been prepared. It provides funds to underwrite a com-

plate overhauling of the North Carolina register of the blind so that much valuable data, most of which has been buried there for some time, can be made available for use. The new register will operate generally along the lines of our preliminary report "The Use of Punch Cards for Registers of the Blind." Specifically, the contract includes

- (1) Hiring of temporary clerical help needed for coding of data, particularly for coding causes of blindness according to the Standard Classification, and for transferring the data from the old register cards and eye reports to the new register cards.
- (2) Hiring an outside agency (probably the North Carolina State Board of Health) to punch and verify some 18,000 statistical cards and to run various tabulations of them.
- (3) Supplies and materials, including punch cards, new register cards, forms, and so forth.

It should be noted that the consultative services of the Biometrics Branch, National Institute of Neurological Diseases and Blindness, are available to all State agencies serving the blind for the purposes of establishing registers or improving those already in existence.

It is hoped that the transfer to punch cards can be finished by July 1. Then the punch cards can be tabulated in order to provide data for the Biennial Report of the Commission. These tabulations cannot include causes of blindness, but a breakdown by age, race, sex and county will be possible. Coding of eye reports will take place later during the year, when assistance from the National Society for the Prevention of Blindness is available with respect to adopting the Standard Classification. This coding should be done, and the punch cards corrected accordingly, before the end of the year. In January 1963 the Commission will be able to prepare the tabulations required for our Model Reporting Area. The Commission will also undertake to maintain the new system, since the contract provides only for the initial expense of transferring the register to punch cards.

A number of other States have expressed an interest in receiving help from the Public Health Service in one form or another for the purpose of improving their registers, or even for the purpose of setting up a register where none is in existence at present. I hope that this review of the North Carolina project will give some idea as to what the National Institute of Neurological Diseases and Blindness is prepared to do in this field.

The North Carolina Register was originally set up as a special project of the WPA under the supervision of the Commission. Thus it represented a capital investment, so to speak, by the Federal Government at that time. The present register, more than 25 years later, is built upon that original capital. Surely this new investment by the Federal Government into the North Carolina Register will also have a long-lasting beneficial effect in furthering the cause of good statistics on the blind.

#### Discussion:

Mr. Meyer inquired as to the comparison of the prevalence rate of blindness in North Carolina with other States. Miss Anderson indicated that the rate was about 2.67 per thousand in North Carolina.

Dr. Quade stated that this rate was higher than that for any other State for which data are available. He pointed out that this rate is based on a wider definition of blindness than the one the Model Reporting Area has adopted, although not very much wider, as Dr. Hurlin remarked. Mr. Goldberg observed that prevalence rates may vary from State to State, at least at the present time, because of varying definitions of blindness and varying degrees of completeness of reporting; special studies are needed in order to examine comparability among States.

Miss Anderson also remarked that her agency administers not just public assistance but also vocational rehabilitation, and it has a medical division charged with responsibility for prevention of blindness and restoration of

sight. Therefore her agency serves a great segment of the population which is not on Aid to the Blind. Naturally, it receives current reports on these people. Furthermore, her agency's medical advisory board includes all the ophthalmologists in the State. These have been indoctrinated from the beginning. They render valuable assistance because they know just about as much about what her agency might offer their private patients as the agency knows itself.

Mr. Meyer inquired as to the extent to which North Carolina gets response to the letters it sends out in its clearance, and as to the reasons for non-response. Miss Anderson indicated that the response was good. When all efforts to locate a registrant have failed, he is placed as an unknown in the inactive file, with those who are deceased, who have moved out of the State, or those who have had vision restored. However, there are very few such unknowns.

## APPENDIX G

### Study of Association Between Factors of Pregnancy, Labor, and Delivery and the Occurrence of Blindness in Children in New York State

Irving D. Goldberg<sup>1</sup>

In the report of a study by C. Edith Korby on the "Causes of Blindness in Children of School Age," which appeared in *The Sight-Saving Review* in 1958, it was stated that throughout the entire series of cases studied "... it has become increasingly evident that *factors affecting early development of the eyes constitute the most important problem in preventing blindness in children.*"<sup>(1)</sup> Her study included more than 4400 school children from kindergarten through high school grades in 1954-1955. The cause of blindness was presumed to be due to prenatal influence in 56% of this study group, of which 42% were due to unspecified prenatal causes and 14% presumed to be of genetic origin. An additional 7% were due apparently to undetermined causes. These findings appear to be similar to those from other sources and, of course, exclude cases of retrolental fibroplasia caused by excess oxygen after birth.

In light of the apparent importance of prenatal and genetic factors as a cause of blindness in children, the Biometrics Branch, National Institute of Neurological Diseases and Blindness, thought it would be most desirable to look into the possibility of conducting research which might shed some light on this matter.

It would have been desirable, of course, to conduct a prospective study by following a group of pregnant women through their pregnancy, and their offspring over a period of years. However, such an approach was completely impractical in view of the long period of followup necessary, and the large number of

pregnancies that would have to be studied because of the relatively low incidence of blindness. Consequently, the approach taken is a retrospective one similar to that employed by Lilienfeld and Parkhurst<sup>(2)</sup> in their study of the association of factors of pregnancy and parturition and cerebral palsy in upstate New York (i.e. exclusive of New York City).

Basically, this retrospective approach employed for the blindness study starts with a group of affected children who were born in New York State during a specified period of years. The birth certificates of these children are searched for information on complications of pregnancy and labor, such information appearing on the confidential medical portion of the certificate. The frequency of specific complications for the case group are then compared with that obtained from birth certificates of a control group composed of a representative sample of all recorded live births in the State over the same time period.

It undoubtedly would have been better to obtain the information on pregnancy and labor from the actual hospital records. However, the number of cases studied and the number of hospitals involved were far too great to make this effort feasible. Although not contained in the present study design, if the results of the study indicate this to be a worthwhile ancillary or supportive procedure, we may attempt to review hospital records for a small sample of cases and controls.

In designing the study, four concerns were

<sup>1</sup>Supervisory Statistician, Biometrics Branch, National Institute of Neurological Diseases and Blindness.



paramount: 1) we had to obtain a large number of blind children, born over a relatively recent time period, for whom information on the probable cause of blindness was determined. Specifically, we wanted to exclude all children whose blindness was known to be due to external causes or other factors not associated with fetal development and the birth process; 2) the cases chosen had to be classified blind according to a commonly accepted definition. It was felt that, insofar as possible, for this study blindness should be defined as vision not greater than 20/200 in the better eye, with best correction, or field of vision restriction of 20° or less; 3) the study had to be confined to a limited geographic area; and 4) the birth certificates on file in this area had to contain the necessary information relating to the prenatal period.

The area chosen for the study was New York State for the following reasons: 1) The New York State Commission for the Blind had maintained a mandatory register since its inception in 1913; and the reporting of blind persons to the Commission became mandatory in 1945. 2) The extremely large register in New York State provided the source of an adequate number of cases for study. 3) The New York State Commission had been employing the Standard Classification of the Causes of Blindness ever since the Classification first appeared in 1940, and had subsequently also adopted the two later revisions of the Classification (1957 and 1960). 4) The legal definition of blindness in New York State was essentially that mentioned above ("A blind person shall be defined as one who is totally blind or has impaired vision of not more than 20/200 visual acuity in the better eye and for whom a diagnosis and medical findings show that vision cannot be improved to better than 20/200; or who has loss of vision due wholly or in part to impairment of field vision or to other factors which affect the usefulness of vision to a like degree"). 5) The medical supplement of both the New York City birth certificate and the New York State birth certificate (applicable to newborn in the State outside of New York City), although slightly different, contained space for recording complications of pregnancy and labor. Further,

revisions to the birth certificates during the period of study were considered to be of minor consequence. Also, questions regarding complications appeared to have been completed on more than 90% of the total birth certificates over the period of study; and 6) Cooperation from the New York State Commission for the Blind, and from the New York City and New York State Departments of Health was assured.

The study objective is to determine whether mothers of blind children are characterized by an excess of selected prenatal and perinatal disorders, that is, the disorders during pregnancy and around the birth period, as compared to mothers of the total population of live births surviving the neonatal period, which is about one month after birth. Because the likelihood of having a very young child who dies very early in infancy reported to the agency is probably very slight, the control group was confined to those surviving the first 28 days of life.

The study population includes about 500 children who met the following five criteria: (1) born during the period 1948 to 1960; (2) classified blind by the State Commission for the Blind during the period 1948 to 1960; (3) having blindness presumed to be due to unspecified prenatal or genetic factors, or to otherwise unknown factors as indicated in the records of the Commission (excluding retrolental fibroplasia and cases presumed to be due to German measles); (4) having birth certificates on file at New York City or New York State Department of Health; and (5) single born.

The control group is a stratified sample of 3 in every 1000 recorded live births in New York State during the period 1948 to 1960, yielding some 12,000 controls in all. Stratification is merely a technical procedure to obtain more information at a reduced cost for analysis.

The information to be collected is represented by the items included on three study forms (see Exhibits 1-3). There will be obtained, for both the cases and controls, certain items appearing on the birth certificates, such as date and county of birth, sex of child, weight at birth, race of mother, age of mother, number of previous children, specific complications of

# APPENDIX G - EXHIBIT I

FORM A

## STUDY OF PERINATAL FACTORS AND BLINDNESS

### PART I. From IBM Listing or Nomenclature Index File

NYSGB Folio Number \_\_\_\_\_

County of Residence \_\_\_\_\_  
Code \_\_\_\_\_ Name \_\_\_\_\_

Sex: 1 ☐ M

2 ☐ F

Date of Birth: 19 \_\_\_\_\_  
year \_\_\_\_\_ month \_\_\_\_\_ day \_\_\_\_\_

Year registered: 19 \_\_\_\_\_

Site \_\_\_\_\_ Etiology \_\_\_\_\_

### PART II. From Case Folders

Case \_\_\_\_\_  
last name \_\_\_\_\_ first name \_\_\_\_\_ middle name \_\_\_\_\_

Mother \_\_\_\_\_  
married name \_\_\_\_\_ first name \_\_\_\_\_ maiden name \_\_\_\_\_

Father \_\_\_\_\_  
last name \_\_\_\_\_ first name \_\_\_\_\_ middle name \_\_\_\_\_

Birthplace \_\_\_\_\_  
city \_\_\_\_\_ county \_\_\_\_\_

hospital \_\_\_\_\_

Address of mother  
 at time of birth \_\_\_\_\_  
street and number \_\_\_\_\_

city \_\_\_\_\_

Agency of referral \_\_\_\_\_

# APPENDIX G – EXHIBIT 1

FORM A

(Back)

Unable to locate ☐ State  
☐ City

Certificate number \_\_\_\_\_ ☐ State  
☐ City

☐ Verified

Certificate number \_\_\_\_\_ ☐ State  
☐ City

☐ Verified

Certificate number \_\_\_\_\_ ☐ State  
☐ City

☐ Verified

Certificate number \_\_\_\_\_ ☐ State  
☐ City

☐ Verified

Certificate number \_\_\_\_\_ ☐ State  
☐ City

☐ Verified

## APPENDIX G - EXHIBIT 2

## Biometrics Branch, NINDB

## STUDY OF THE ASSOCIATION BETWEEN PERINATAL FACTORS AND BLINDNESS IN CHILDREN

YEAR	BOROUGH	CERTIFICATE NUMBER
1 19 <input type="text"/> <input type="text"/>	3 0 <input type="checkbox"/> Bronx 1 <input type="checkbox"/> Brooklyn 2 <input type="checkbox"/> Manhattan 3 <input type="checkbox"/> Queens 4 <input type="checkbox"/> Staten Island	4 <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>

  

SEX  9 <input type="checkbox"/> 1 Male 2 Female	PLURALITY AND ORDER  10 <input type="checkbox"/> Number of children born of this pregnancy  11 <input type="checkbox"/> If more than one, number of this child in order of birth	DATE OF BIRTH _____ month _____ day _____ year  DATE OF DEATH _____ month _____ day _____ year  12 <input type="checkbox"/> Not recorded _____
--	--	---

  

MOTHER  RACE 13 <input type="checkbox"/> 1 White 2 Nonwhite 9 Not stated	AGE 14 <input type="text"/> <input type="text"/> Not stated _____
---	--

  

NUMBER OF PREVIOUS CHILDREN  16 <input type="text"/> <input type="text"/> Total born alive 18 <input type="text"/> <input type="text"/> Now living 20 <input type="text"/> <input type="text"/> Born dead (total)	_____ Less than 20 weeks _____ 20 weeks or more
---	--

TO BE FILLED OUT BY BIOMETRICS BRANCH, NINDB - CASES ONLY

Case number \_\_\_\_\_

Checked by \_\_\_\_\_

NYSCB folio number \_\_\_\_\_

Date \_\_\_\_\_

Year registered \_\_\_\_\_

SITE

ETIOLOGY

Year classified 22  24   27

## APPENDIX G - EXHIBIT 2

## Biometrics Branch, NINDB

## STUDY OF THE ASSOCIATION BETWEEN PERINATAL FACTORS AND BLINDNESS IN CHILDREN

## CONFIDENTIAL MEDICAL REPORT

X Left blank

0 Filled out, but no complications  
of pregnancy (as listed below)  
recorded1 At least one complication  
recorded

## COMPLICATIONS OF PREGNANCY

- ☐ Pre-eclampsia  
☐ Eclampsia  
☐ Hypertensive disease  
☐ Uterine bleeding (before labor)  
☐ Pyelitis  
☐ Nephritis  
☐ Heart disease  
☐ Diabetes  
☐ Syphilis  
☐ Tuberculosis  
☐ German measles (Rubella)

 Trimester 1 2 3 Not stated  
☐ ☐ ☐ ☐

- ☐ Other viral  
 Infection  
 Trimester 1 2 3 Not stated  
☐ ☐ ☐ ☐

☐ Injury or operation, specify:

☐ Neoplasm, specify:

- ☐ Pernicious vomiting  
☐ Anemic  
☐ Other, specify:

## RH FACTOR

- ☐ X Not stated  
 0 No test  
 1 Rh+  
 2 Rh-

## COMPLICATIONS OF LABOR

- 48 ☐ None  
 49 ☐ Placenta previa  
 50 ☐ Prem. separation of placenta  
 51 ☐ Prolapse of cord  
 52 ☐ Anomaly of cord  
 53 ☐ Breech presentation  
 54 ☐ Other malpresentations  
 55 ☐ Contracted pelvis  
 56 ☐ Other dystocia  
 57 ☐ Postpartum hemorrhage  
 58 ☐ Other, specify:

## OPERATIVE PROCEDURES

- 59 ☐ None  
 60 ☐ Low forceps  
 61 ☐ Mid forceps  
 62 ☐ High forceps  
 63 ☐ Forceps, plane not stated  
 64 ☐ Cesarean section  
 65 ☐ Breech extraction  
 66 ☐ Internal version and extraction  
 67 ☐ Other, specify:

## WEIGHT AT BIRTH

 68     grams or  
 \_\_\_\_\_ lbs. \_\_\_\_\_ ounces

## CONGENITAL ABNORMALITY

- 72 ☐ If yes, describe:  
 0 No  
 1 Yes  
 2 Questionable

## BIRTH INJURY

- 73 ☐ If yes, describe:  
 0 No  
 1 Yes  
 2 Questionable

Filled out by \_\_\_\_\_

Date \_\_\_\_\_

APPENDIX G - EXHIBIT 3

Biometrics Branch, NINDB

STUDY OF THE ASSOCIATION BETWEEN PERINATAL FACTORS AND BLINDNESS IN CHILDREN

NAME (needed only for controls born 1948 or 1949)			1 <input type="checkbox"/> DEATH	
2 <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> Certificate Number			Not recorded _____ Date of death: _____ month _____ day _____ year	
8 <input type="text"/> <input type="text"/> County _____			Checked by _____ Date _____	
SEX  10 <input type="checkbox"/>  1 Male 2 Female	THIS BIRTH  11 <input type="checkbox"/>  1 Single 2 Twin 3 Triplet	IF TWIN OR TRIPLET  12 <input type="checkbox"/>  1 1st 2 2nd 3 3rd	DATE OF BIRTH  13 19 <input type="text"/> <input type="text"/> _____ month _____ day	
MOTHER OF CHILD  RACE  15 <input type="checkbox"/> 1 White 2 Nonwhite 9 Not stated		AGE  16 <input type="text"/> <input type="text"/>		WEIGHT OF CHILD AT BIRTH  18 <input type="text"/> <input type="text"/> <input type="text"/> Grams or _____ lbs. _____ ozs.  Not stated _____
CHILDREN PREVIOUSLY BORN TO THIS MOTHER  22 <input type="checkbox"/> <input type="checkbox"/> Now living 24 <input type="checkbox"/> <input type="checkbox"/> Born alive, now dead 26 <input type="checkbox"/> <input type="checkbox"/> Still born (after 20 weeks)				

TO BE FILLED OUT BY BIOMETRICS BRANCH, NINDB - CASES ONLY

Case number _____	Checked by _____
NYSCB folio number _____	Date _____
Year registered _____	
Year classified _____	SITE 30 <input type="text"/> <input type="text"/>
28 <input type="text"/> <input type="text"/>	ETIOLOGY 33 <input type="text"/> <input type="text"/>

APPENDIX G - EXHIBIT 3  
Biometrics Branch, NINDB

## STUDY OF THE ASSOCIATION BETWEEN PERINATAL FACTORS AND BLINDNESS IN CHILDREN

## CONFIDENTIAL MEDICAL REPORT

- 35 ☐ X Left blank  
 0 Filled out, but no complications of pregnancy (related or not related) recorded  
 1 At least one complication recorded

## COMPLICATIONS OF PREGNANCY

- 36 ☐ Pre-eclampsia  
 37 ☐ Eclampsia  
 38 ☐ Hypertensive Disaease  
 39 ☐ Nephritis  
 40 ☐ Pernicious vomiting  
 41 ☐ Pyelitis  
 42 ☐ Anemia  
 43 ☐ Heart Disease  
 44 ☐ Diabetes  
 45 ☐ Syphilis  
 46 ☐ Tuberculosis  
 47 ☐ Uterine bleeding (before labor)  
 48 ☐ German measles (Rubella)  
 49 ☐ Other viral infection, specify:  
 50 ☐ Injury or operation, specify:  
 51 ☐ Neoplasm, specify:  
 52 ☐ Other, specify:

## RH FACTOR

- 53 ☐ X Not stated  
 0 No test  
 1 Rh+  
 2 Rh-

## COMPLICATIONS OF LABOR

- 54 ☐ None  
 55 ☐ Placenta previa  
 56 ☐ Prem. separation of placenta  
 57 ☐ Prolapse of cord  
 58 ☐ Anomaly of cord  
 59 ☐ Breech presentation  
 60 ☐ Other malpresentations  
 61 ☐ Contracted pelvis  
 62 ☐ Other dystocia  
 63 ☐ Postpartum hemorrhage  
 64 ☐ Other, specify:

## OPERATIVE PROCEDURES

- 65 ☐ None  
 66 ☐ Low forceps  
 67 ☐ Mid forceps  
 68 ☐ High forceps  
 69 ☐ Forceps, plane not stated  
 70 ☐ Cesarean section  
 71 ☐ Breech extraction  
 72 ☐ Internal version and extraction  
 73 ☐ Other, specify:

## BIRTH INJURY

- 74 If yes, describe:  
☐  
 0 No  
 1 Yes

## CONGENITAL MALFORMATION

If yes, describe:

- 75  
☐  
 0 No  
 1 Yes

Filled out by \_\_\_\_\_  
 Date \_\_\_\_\_

pregnancy and specific complications of labor, operative procedures, Rh factor, presence or absence of congenital abnormality or birth injury.

In addition, for the cases only, we will collect information on the cause of blindness — that is, the site or type and the etiology — and the year classified as blind. This information will be obtained from the State Commission's records.

In terms of analysis, a comparison will be made between the cases and controls on factors mentioned, and, insofar as possible, different categories of blindness by site or type and etiology, will be studied separately.

With regard to the current status, information on cases has been obtained from the Commission. Birth certificates for cases have not, as yet, been searched in New York City and New York State; however, the abstracting of data on the control sample is under way in New York City and will begin in upstate New York in April 1962.

#### Discussions:

Dr. Ferree commented that he thought the matter of studying blindness in the perinatal period is probably going to offer, as time goes on, a tremendous opportunity for prevention. Also, he thought it raises a question of some importance to which he hoped all the participants might be giving some thought. He felt that the

medical profession, by and large, is not as aware as they might be of the opportunities here for prevention. He thought the participants could do a lot to help point up a problem which has come to his attention. The problem, which may be considered delicate, has to do with the counselling of blind people who are getting married and having children. Dr. Ferree stated that there has been enough work in the area of prognosticating what the results are in marriages to be hopeful in this regard. He recognizes that this matter raises certain problems of freedom of expression and so forth, and he does not know at this point how this kind of problem can be attacked directly. However, the subject has been brought to his attention and he thinks, with the increasing knowledge in genetics and related fields, that more attention should be given to the matter.

#### REFERENCES

- (1) C. Edith Kerby. Causes of Blindness in Children of School Age. *Sight-Sav. Rev.* XXVIII, No. 1: 1-12, 1968.
- (2) Lillienfeld, A. M. and Parkhurst, E. A Study of the Association of Factors of Pregnancy and Parturition with the Development of Cerebral Palsy — A Preliminary Report. *A. J. Hyg.* 53, No. 3: 262-282, 1951.



## APPENDIX H

### Study of Survivorship and Causes of Death Among the Blind in Massachusetts

Eugene Roget<sup>1</sup>

To our knowledge, there is very little statistical information available on survivorship patterns or causes of death among the blind. Although studies have been conducted in this general area, the most recent one we know of which appears to have been based on a sufficient number of cases is a study by the Metropolitan Life Insurance Company during the period 1923 to 1933. This study relates to the experience of some 11,000 Industrial policyholders who were granted disability allowances because of blindness incurred subsequent to the issue of their policies.

As a group, it was found the death rate of these blind policyholders was two and one half times that of all Industrial policyholders.

Although no actual tabulations were presented, a number of other findings were reported in this study. For blind children, a very marked excess in mortality was noted, with an extremely high death rate from cancer. For all ages the causes of death which showed the highest mortalities, as compared with normal, were syphilis, diabetes, diseases of the arteries, and chronic nephritis.

The eye condition most frequently reported as the cause of blindness was cataract. Next in importance was glaucoma, and, third, atrophy of the optic nerve.

These results were reported in the September 1935 Statistical Bulletin of the Metropolitan Life Insurance Company.

Our study is similar in some respects to this earlier one, but has the advantage, we believe, of relying on a less selective type of population.

This study is being conducted with the help and cooperation of the Massachusetts Division of the Blind, and also the Massachusetts Office of Vital Statistics. Our study objectives are twofold: first, to determine survival rates for blind persons by age, sex, and cause of blindness, and compare these with corresponding rates observed in the general population. Second, to determine the distribution of causes of death among blind persons by age, sex, and cause of blindness, and compare with corresponding distributions observed in the general population.

The sources of information are records of the Massachusetts Division of the Blind, death certificates from the Massachusetts Vital Statistics Office, and published data from the National Office of Vital Statistics Division.

The study population consists of all persons first registered blind by the Massachusetts Division of the Blind between January 1, 1940, and December 31, 1959. The closing date for followup is December 31, 1961. This should provide about 12,000 blind persons of all ages, who will have been observed for differing periods of time up to 22 years from the date registered as blind by the Massachusetts Division of the Blind.

It is estimated that approximately 5,000 deaths will have occurred in the study group between January 1, 1940, and December 31, 1961.

The definition of blindness to be used is the legal definition in Massachusetts, namely,

<sup>1</sup>Analytical Statistician, Biometrics Branch, National Institute of Neurological Diseases and Blindness.

# APPENDIX H - EXHIBIT 1

## STUDY OF SURVIVORSHIP AND CAUSES OF DEATH AMONG THE BLIND IN MASSACHUSETTS

1. Case # \_\_\_\_\_

2. Name \_\_\_\_\_

3. Date of birth \_\_\_\_\_

4. Date registered \_\_\_\_\_

5. Last Mass. address \_\_\_\_\_ (date) \_\_\_\_\_ (street and number) \_\_\_\_\_ (town or city) \_\_\_\_\_

6. Status on 12/31/61 ☐ Active ☐ Died \_\_\_\_\_

☐ Sight restored \_\_\_\_\_ ☐ Unable to locate \_\_\_\_\_

☐ Moved out of state \_\_\_\_\_ (address) \_\_\_\_\_

7. Sex ☐ Male ☐ Female 8. Age at loss of sight \_\_\_\_\_ 9. Place of birth: \_\_\_\_\_ 10. Eye report in file ☐ Yes ☐ No

11. Cause of blindness: Affection \_\_\_\_\_ Code \_\_\_\_\_ Etiology \_\_\_\_\_ Code \_\_\_\_\_

12. Vision RE \_\_\_\_\_ LE \_\_\_\_\_ Abstracted by \_\_\_\_\_ Date \_\_\_\_\_ (mo) \_\_\_\_\_ (da) \_\_\_\_\_ (yr)

13. Death Certificate Val. \_\_\_\_\_ Pg. \_\_\_\_\_ ☐ Not found

14. Place of death \_\_\_\_\_ (town or city) \_\_\_\_\_

15. Date of death \_\_\_\_\_ (mo) \_\_\_\_\_ (da) \_\_\_\_\_ (yr)

16. Race ☐ White ☐ Nonwhite ☐ Not stated

### CAUSES OF DEATH

17. Cause \_\_\_\_\_

18. Due to \_\_\_\_\_

19. Due to \_\_\_\_\_ 20. Code \_\_\_\_\_

21. Other Sign. Conditions \_\_\_\_\_

22. Comments (indicate by item no.) \_\_\_\_\_

Abstracted \_\_\_\_\_

Date \_\_\_\_\_ (mo) \_\_\_\_\_ (da) \_\_\_\_\_ (yr)

corrected vision of 20/200 or less in the better eye, or peripheral field of vision contracted to 20° diameter or less, regardless of visual acuity. This is the Model Reporting Area definition.

Our control group will be the general population in Massachusetts. Survival rates will be computed based on the 1949-51 life tables for Massachusetts. The distribution of deaths by underlying cause of death will be obtained from Massachusetts for the entire study period

from published data.

Information to be collected includes date of birth, sex, race, date of registration, visual acuity, cause of blindness (by site and by etiology), date and reason for removal, and underlying cause of death. (See Exhibit 1)

Data collection began in January 1962 and is expected to continue for some months yet. There are three statistical clerks now employed on this work.

## APPENDIX I

### The Need for Good Statistics on the Blind

Irving D. Goldberg<sup>1</sup>

I should like to open my remarks by referring to a paper by Dr. Sidney Cutler of the National Cancer Institute on "The Role of Morbidity Reporting and Case Registers in Cancer Control." (1) Dr. Cutler began his paper with the following statement:

"That no community can effectively prevent or control disease without knowledge of the number, location, and characteristics of cases is generally accepted. Information on the incidence of new cases is needed to prevent the spread of a communicable disease. Data on the relative incidence of a disease in various segments of the population are necessary for planning a productive and economical case-finding program. Information on the total number of persons with a disease is required for evaluating the adequacy of community resources."

There is little doubt that Dr. Cutler's comments are directly applicable to the importance of accurate and uniform statistics on the blind. Indeed, on various occasions in the past, and earlier today, Dr. Ferree and Mr. Barnett have indicated the importance of adequate statistics as such data relate to their respective agencies and to the nation as a whole. The need for such statistics was indicated or implied in the interesting presentations this morning by Dr. Harlin and Mr. Magill. In 1957 Miss Penney and Miss Anderson, from the North Carolina Commission for the Blind, reported on the use of their register in providing statistics of value to a blindness

prevention program. (2) And Mr. Mungovan, as Director of the Massachusetts Division of the Blind, pointed to the need for more adequate statistics on blindness when he was invited to appear before a Congressional Subcommittee on Special Education in 1959.\* I quote from Mr. Mungovan's testimony:

"I recommend that a careful statistical study be made nationally of the incidence of blindness and the incidence of partial sight and that this study classify blind and partially sighted persons by age, sex, cause of blindness and vocational potential and the goals of those blind and partially sighted people. It is not sufficient for program planning purposes to work on an estimate that there are 300,000 blind persons in the United States without describing more accurately who are these blind people. Data available in Massachusetts could be a stepping stone to such a study...." (3)

I hope, and I feel sure, Mr. Mungovan, that the Model Reporting Area will use this stepping stone to such advantage.

It is evident from these few observations alone, that the need for good statistics on the blind is not peculiar to any level of government nor to any specific organizations or groups. Much rather, it is basic to all interested agencies: official or voluntary; local, State, Federal or international; and to all interested professional and lay groups as well.

Since our efforts to obtain these needed data rely on blindness registers as their source, it seems desirable at this point to comment

<sup>1</sup>Supervisory Statistician, Biometrics Branch, National Institute of Neurological Diseases and Blindness.  
<sup>2</sup>Subcommittee on Special Education of the Committee on Education and Labor, U. S. House of Representatives, December 17, 1959, New Haven, Connecticut.

briefly on the function of a well-organized register. A good register of the blind should be so organized, and should contain such information, as to enhance the administration of a service program. At the same time, it should provide statistical information, not only for the planning and evaluating of a service program, but for determining the magnitude and nature of the blindness problem. To do one without the other, that is to serve solely as either a service or statistical tool, it seems to me, results in a loss of valuable potential in the prevention, control and treatment of blindness.

The specific components of an adequate register are too detailed for presentation at this time. However, I cannot resist mentioning one of the major essentials to a blindness register, if it is to become, to the fullest extent, a feasible and successful venture. This essential is a continuing procedure designed to keep the register up to date. In this respect it may be noted that attempts to publicize, through the professional and lay community, the services available to the blind, and continuous and periodic attempts to extend such services to the blind population, acts as a means for updating the register, and hence, for providing accurate up-to-date information on the prevalent blind.

With these introductory remarks, I should like to turn now to the various needs served by an adequate up-to-date register. In this regard, it is well to note that the needs of the States, the Federal Government, the national and local voluntary agencies, and other interested groups, cannot all be satisfied without uniformly and accurately collected data based on a uniform definition of blindness. These needs may be grouped into two broad categories: a) administrative and service, and b) research.

The administrative and service needs may be indicated as follows:

1. A register can be useful in pinpointing specific hazards that cause blindness, and thus help to promote legislation for the control of such hazards as well as to set up programs of education, prevention, and control. For example, it may provide the justification for setting up glaucoma detection clinics, low-

vision aid clinics, industrial safety programs, etc. Furthermore, good data on the magnitude of the problem of blindness are of first importance in planning and administering programs of assistance, and in planning blindness prevention programs intelligently. Such statistics are essential in evaluating the results of measures taken to control blindness.

2. It is useful in determining trends in caseloads and, hence, in projecting the type and number of staff needed in the blindness agency, in preparing and justifying present and future budget needs, and in estimating the future need for educational and other facilities for the blind.

3. It provides a means for obtaining statistics that are an aid in program orientation. For example, data on the distribution of the blind by cause and age are helpful in determining program emphasis as it concerns rehabilitation, problems among the aged blind, etc. Also of interest in this connection is information relating to the coexistence of other handicapping conditions among the blind.

4. The register will also provide statistics to show, for each county or other political subdivision, the number of cases on the register, as well as additions and removals of blind individuals on an annual or other periodic basis. Figures on register incidence or prevalence by county help to tailor the total program to the needs of specific areas throughout the State. Thus, a suitable use of the register would point out geographic areas or specific population groups with high incidence or prevalence of blindness according to age, sex, or race. These would be warning signals and would be helpful in determining areas or population groups that might need intensive case-finding or preventive programs.

In this connection, and in passing, I might note that the Biometrics Branch is now analyzing the reported blindness prevalence rates in North Carolina (as of June 30, 1960) by county according to broad age groups (under 65 years and 65 years or over). Some difference among counties appear to be showing up. However, these data have not as yet been analyzed fully, and we do not know at this time whether those differences may be real or due to chance

riation or to artifacts of reporting. Additional geographic analyses by sex and race also will be made utilizing published data from North Carolina. Similar attempts will be made for other localities where adequate data are available.

5. The register would provide descriptive statistics of the population served, such as by age, sex, race, cause of blindness, degree of vision, etc., for inclusion in annual and other periodic reports, for the entire program or for special programs such as vocational rehabilitation, preschool children, etc. Also, as a result of register studies over time, it may be possible to project into the future estimates of the blind according to various characteristics.

6. It is useful in public relations by providing information for presentation to various lay and professional groups, indicating the magnitude of the problem in their respective communities. In this regard, it should be noted that feedback of information to ophthalmologists, optometrists, and other professional groups should help to stimulate better and more complete reporting of referral.

7. The register is useful in answering requests from individuals and from public, private and voluntary agencies for information on the magnitude of the problem by county, age, sex, cause of blindness, etc.

8. The register is useful for providing specific information quickly to appropriate public and voluntary agencies, relating to an individual's blindness status, services received, etc.

9. The register is useful in determining whether individuals referred for service have previously been registered, and what specific information is available. Thus, the register serves a case-control function.

10. The register is useful in maintaining a record of services given over specified time periods, in determining what proportion of the blind are receiving specified types of service, such as Aid to Blind, vocational rehabilitation, talking books, etc.

11. The register is useful in relating services to characteristics of individuals served.

Now, what about the research needs that are served by an adequate up-to-date register?

An indication of the kind of research needs that can be satisfied by a register are the different studies, utilizing register data, which are now being planned, are already under way, or have been completed. A few of these studies are as follows:

1. The association between perinatal factors of pregnancy, labor and delivery and the occurrence of blindness in children (described in Appendix G).
2. Survivorship and causes of death among the blind (described in Appendix H).
3. Diabetes as a cause of blindness.
4. Life span and rehabilitation potential of blind diabetics.
5. Clients' job satisfaction after receiving vocational rehabilitation services.
6. A ten-year followup study of blind persons to determine length of survivorship (especially among blind diabetics); effect of rehabilitation services; educational, social and other characteristics of the blind; etc.

Undoubtedly many of you are aware of a number of other studies made possible by registers of the blind.

It should be strongly emphasized that appropriate study designs are essential in setting up the planned research. Questions relating to the reliability of data, sampling, bias, analytical procedures, etc., must be resolved before a study is undertaken. The help of competent statisticians should be sought before, during, and after data collection.

At this point I should note that a by-product, so to speak, of no little importance, is recognition an agency achieves, as the source of this valuable information on the blind.

The question now arises as to just how the Model Reporting Area for Blindness Statistics will serve the above-mentioned needs. The Area is founded on the concept that reliable meaningful statistics, comparable from State to State, are urgently needed. Dr. Ferree has, in the past, indicated that the National Society has long recognized the need for more reliable statistics on blindness for planning and evaluating preventive programs, and the need for projecting the estimates of blindness for the nation more reliably than is possible now.

This, it is hoped, the Model Reporting Area will ultimately achieve. When States agree to agree, almost nothing is impossible. It is believed that administrative, service, and research needs will be served by data collected by the Model Reporting Area States to a far greater degree than is now possible.

There will still be a continuing need to make estimates for States not in the Area. It is hoped that as such States see the great advantage to themselves as well as to others in the collection of uniform statistics, and thus agree to standards to which all can repair, the cause of good statistics on the blind will be better served.

## REFERENCES

- (1) Cutler, Sidney J. The Role of Morbidity Reporting and Case Registers in Cancer Control. Publ. Health Rep. 65, No. 34: 1084-1089, 1950.
- (2) Penney, A. R. and Anderson, C. The Register of the Blind: Its Use in a Prevention Program. Sight-Saving Rev. XXVII, No. 4: 214-217, 1950.
- (3) Division of the Blind. Annual Report. Boston, Massachusetts Department of Education, 1950.

## APPENDIX J

### List of Participants

#### FIRST ANNUAL CONFERENCE MODEL REPORTING AREA FOR BLINDNESS STATISTICS March 26-27, 1962

##### State Agencies\*

##### Connecticut Board of Education of the Blind

Genevieve M. Daley, Supervisor of Clerical  
Section  
H. Kenneth McCollam, Executive Secretary

##### Delaware Commission for the Blind

Dr. F. J. Cummings, Executive Secretary  
Beatrice F. Simonds, Senior Secretary

##### Kansas Department of Social Welfare

Gordon Grabhorn, Administrative Asst., Di-  
vision of Services for the Blind  
Barbara Wickberg, Director, Division of Re-  
search and Statistics

##### Louisiana Department of Public Welfare

William V. Bridges, Director, Bureau for the  
Blind & Sight Conservation  
Evalena Ford, Medical Social Consultant for  
Eye Services

##### Massachusetts Department of Education

John F. Mangovan, Director, Division of the  
Blind  
Michael Sullivan, Supervisor of Research,  
Division of the Blind

##### New Jersey Commission for the Blind

Mary Elliott, Senior Clerk  
George F. Meyer, Executive Director

##### North Carolina Commission for the Blind

Christine Anderson, Supervisor, Social Ser-  
vice Division  
Carlton F. Edwards, Administrative Officer

##### Rhode Island Department of Social Welfare

Eva M. DeTommaso, Bureau for the Blind  
Eleanor M. Johnson, Administrator, Bureau  
for the Blind

\*Hawaii and New Hampshire were unable to send representatives to the Conference because of  
pressure of work and illness.



**Vermont Department of Social Welfare**

Virginia Cole, Director, Division of Services  
for the Blind

**National Voluntary Agencies**

**United States**

**American Foundation for the Blind**

M. Robert Barnett, Executive Director  
Dr. Milton D. Graham, Director, Division of  
Research & Statistics  
Alexander F. Handel, Director, Division of  
Community Services  
Dr. Eric Josephson, Research Associate,  
Division of Research & Statistics  
Richard E. Onken, Research Assistant, Di-  
vision of Research & Statistics

**National Society for the Prevention of Blindness**

Dr. John W. Ferree, Executive Director  
Elizabeth M. Hatfield, Consultant in Statis-  
tics  
Dr. Ralph G. Hurlin, Chairman, Committee  
on Operational Research

**Canada**

**Canadian National Institute for the Blind**

Joyce Hickling, National Supervisor, Preven-  
tion of Blindness and Eye Service Depart-  
ment  
Arthur N. Magill, Superintendent, Ontario  
Division

**Federal Agencies**

**Library of Congress**

Robert S. Bray, Chief, Division for the Blind  
Charles Gallozzi, Assistant Chief, Division  
for the Blind

**Office of Education, Department of Health,  
Education, and Welfare**

John W. Jones, Specialist, Education of the  
Visually Handicapped, Services for Ex-  
ceptional Children and Youth

**Office of Vocational Rehabilitation, Department  
of Health, Education, and Welfare**

Celia Sperling, Analytical Statistician, Di-  
vision of Statistics and Studies  
George A. Magers, Division of Services for  
the Blind

**Social Security Administration, Department of  
Health, Education, and Welfare**

E. Myles Cooper, Chief, Division of Program  
Statistics & Analysis, Bureau of Family  
Services  
John M. Lynch, Chief, Assistance Analysis  
Branch, DPSA, BFS  
Dr. Robert H. Mugge, Survey Statistician,  
Assistance Analysis Branch, DPSA, BFS

**Public Health Service, Department of Health,  
Education, and Welfare**

**Bureau of State Services**

James Miller, Acting Chief, Program Studies  
Section, Neurological and Sensory Disease  
Service Branch

Quentin R. Remoin, Research Grants Of-  
ficer, Division of Chronic Diseases

National Institute of Mental Health

Dr. Morton Kramer, Chief, Biometrics Branch

Earl S. Pollack, Chief, Hospital Studies  
Section, Biometrics Branch

National Institute of Neurological Diseases  
and Blindness

Irving D. Goldberg, Supervisory Statistician,  
Biometrics Branch

Dr. Hyman Goldstein, Chief, Biometrics  
Branch

Dr. Richard L. Masland, Director

Dr. Dana Quade, Analytical Statistician,  
Biometrics Branch

Eugene Rogot, Analytical Statistician, Bio-  
metrics Branch

Public Health Service Publication No. 973